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Indigenous Voices on the Moral and Ethical Horizon of the Land: A Contextualized Land Acknowledgement

Leanne Poitras Kelly, Mona Lisa Bourque Bearskin, Lisa Perley-Dutcher, Bernice Downey, and Christina Chakanyuka

“TOWARD A MORAL HORIZON” SEEMS A FITTING TITLE as we begin this ethical exploration together. Gazing towards a metaphorical horizon must also include the conspicuous land horizon on which so many of these ethical issues arise.

In this era of what settlers have termed “reconciliation,” Indigenous communities are asserting their own critiques of conciliatory discourse, invitations to the power tables, and yes, the creation and inclusion of land acknowledgements within our institutions. Those critiques are complex. Creating a land acknowledgement can be an empowering and a supportive strategy to elevate and advance original land stewardship and Indigenous community recognition. It can also be performative and used as a tool to bypass real engagement with community issues.
To locate oneself with authenticity in a land acknowledgement, we assert that truth must precede reconciliation discourse. Those who truly wish to reconcile must first recognize the truth that the land on which we work, live, and play is inherently Indigenous land. It is our moral and ethical responsibility to recognize and articulate our relationship to this truth.

Settler pursuit of economic gains through the use of this land and its resources bears witness to Indigenous exclusion. Indigenous communities experienced social, political, economic, and cultural segregation. Our ancestors faced urgency for survival when confronted with the power of European settlement, creation of Treaties, and the mechanisms of coercion and imposed community controls. As a collective, Canadians all live under these Treaties and agreements, which place parameters unique to Indigenous Peoples that go beyond “equity, diversity, and inclusion” initiatives. We are all involved in a relationship sculpted through colonization that needs to be made whole through restitution and justice.

Yet, Indigenous communities persist, despite all acts of oppression and attempts at genocide. Indigenous Peoples and communities know the power of resistance, ceremony, relationship, and solidarity, and the power of our Earth Mother. We are all connected, and what we do to our land, we do to ourselves and each other. Our stories have existed through our ancestors since time immemorial. Our resilience demonstrates our reliance on the gifts of ancestral strength, blood memory, and willingness to reach beyond socially constructed barriers. Our stories are foundational stories of Canada.

Acknowledging the past and current relationships with Indigenous Peoples is part of an ethical awakening that goes beyond reciting a well-crafted and well-intentioned land acknowledgement. We acknowledge that there is much work to do, and that Indigenous people cannot labour alone, nor remain invisible to mainstream society. Nurse leaders have a role to play in creating a moral horizon that is more equitable and ethical. We encourage readers of this book to begin embodying this relationship by creating their own land acknowledgement founded in their own inquiry and pursuit of justice.
The writers of this acknowledgement are located across this land on unceded and unsurrendered Wolastoqey territory, unceded and occupied Stz’uminus territory, unceded and occupied territory of the T’kumlups te Secwepemc, and the unceded and occupied territory of the Chippewa, Odawa, Potawatomi and Delaware, and Oneida Nations. As a collaboration of five Indigenous nurse scholars, we acknowledge the great expanse of this land now called Canada. Using our collaborative Indigenous nurse voices, we invite readers to investigate their own relationship to the land. We encourage readers to interrogate assumptions shaped by patriarchy and colonialism and to pursue authentic engagement and relationships with Indigenous people and community issues based on intentional inquiry, honesty, humility, and respect.

The editors of this book reside on the occupied and unceded territory of the Musqueam, Squamish, and Tsleil-Waututh First Nations and the W’SANEC, Esquimalt and Songhees First Nations. The supporting educational institution, the University of Victoria, is located on unceded and occupied territory of the Coast Salish, specifically the communities of the W’SANEC, Esquimalt, and Songhees Peoples. This land historically held village sites that reached beyond the land borders created by the Indian Act and federal government allocations. The Coast Salish Peoples continue to live and have relationships with other Vancouver Island First Nations, settler communities, and beyond. Throughout Canada, Indigenous Peoples maintain their connection to the land and language and persist in their claim to the resources of their traditional territories and their right to prosper and flourish as we look toward this moral horizon.
IN 2008, I HAD THE PLEASURE of attending the 12th International Nursing Philosophy conference in Boston. Eminent nurse ethicist Dr. Anne Davis, a native of Boston, offered to escort me and another nurse ethicist, Dr. Joan McCarthy, on a visit to Salem as we had expressed interest in learning more about the 17th-century Salem witch trials. We arranged to meet at Boston harbour to catch the Salem ferry. I arrived at the appointed time to find Anne and Joan waiting and with a question: “Have you taken your sea sickness medication?” My response? It was along the lines of, “No need, thank you, I’m a fisherman’s daughter.” My recollection of the rough ride that followed comprised repeated instructions to “look at the horizon”; a disconcerting awareness that the “horizon” alternated between a turbulent sea and an angry sky; and the experience of severe sea sickness. I am pleased to report that my fellow travellers agreed that we could take the train back to Boston.

I was reminded of this “humility story” as I read the chapters of this edition of Toward a Moral Horizon: Nursing Ethics for Leadership and Practice. The first edition of this wonderful book, published in 2004, predated my Boston adventure and much has changed since then. The metaphor, however, of nursing ethics as a journey toward a moral horizon remains pertinent and current. The idea of navigation and of nurse leaders being the moral compass for nurses, “using their power as a positive force to promote, provide and sustain quality practice environments for safe, competent, and ethical practice”
This third edition of the book comes at a time characterized by crisis, conflict, and complexity. “Crisis” is ever-present in discussions of global phenomena that impact health and care. We are emerging from the sars-CoV-2 pandemic, which resulted in the deaths of millions of people, including nurses and other caregivers. We are in the midst of a climate emergency, whereby our environment is ravaged and irreparably damaged by human activity. We also have a significant care crisis with needs for health and social care escalating and the availability and sustainability of the care workforce in jeopardy (Buchan et al., 2022). In addition, we have war in Ukraine and political unrest and conflict in other parts of the globe, resulting in great suffering, strain on health services, and stress for nurses. Whilst we can be proud and appreciative of increased longevity in many parts of the world, this brings with it increased complexity and inequities and the need for agile, responsive health systems in which care providers are sensitive to individual and community diversity and committed to addressing inequities. The authors of this book make explicit the what, why and how of nurse leaders’ critical contributions to responses to crisis, conflict, and complexity.

It is argued in this third edition that “an ethical goal for nurses in advanced practice roles is to understand, and ultimately address, the cumulative effects of inequities at individual (micro), organizational (meso), and larger societal (macro) levels” (Chapter 1). Another goal, as stated in the Introduction of this text, is enabling nurses and other health care providers to become “ethically fit.” The authors draw on the work of Kidder (2009), who reminds us that ethics is not promoted by one-off inoculations but rather, like physical exercise, requires repeated committed activity, albeit with the addition of critical thinking and reflection. The complexity of ethical or moral competence in nurse leadership is implied with a range of rich insights shared regarding how the “oughtness” of health care practice can be conceptualized. The starting point for the authors’ approach to nursing ethics is the centrality of relationality in understandings of persons and perspectives on social justice which accommodate an ethics of care. The inclusion of
Indigenous voices in this third edition enable new areas of wisdom to be integrated into the field of nursing ethics. These Indigenous voices remind us that we should “walk softly on the land,” (Chapter 5), take ethical responsibility to interrogate our positions, and commit to safeguarding our environment.

The breadth and depth of ethical issues explored, the frameworks discussed, and the extended range of topics included, make this third edition, now in an open access, digital format, an invaluable resource for nurse leaders, practitioners, educators, and researchers. Although the authors focus on the Canadian context, the three sections of the book have international appeal. The first section, “Mapping the moral climate for health care and nursing ethics,” for example, sets the scene with discussions of the professional and social context of nursing practice, research ethics, public health, and Indigenous perspectives. The second section, “Pursuing equity in diverse populations” is where the focus is on important debates in relation to nurse education, the promotion of equity, addressing structural inequities, mental health, reproductive justice, the moral agency of young people, home health care, care of people with disabilities, care of older adults, and care of those at the end of life. In the third and final section, “Navigating horizons for health care and nursing ethics,” the authors explore some of the most challenging ethical issues relating to current and future developments affecting health care, such as genetics, xenotransplantation, digital health technologies, and globalization.

The abundance of scholarly riches in this book is made possible by the experience, expertise, and wisdom of three nurse ethicists with exemplary international reputations. Their scholarship, over many years, illuminates many pressing issues relating to bioethics, health care, and nursing. We can be grateful for their decision making, which resulted in the inclusion of 32 additional expert authors with diverse, wide-ranging, and enriching perspectives.

This Foreword opened with a story relating to a boat journey—a journey scuppered by over-confidence and unpreparedness—a journey with a turbulent sea and a less than clear horizon upon which to focus. It is a story resulting in a less than positive outcome which required an alternative resolution strategy. The story serves as a humbling metaphor for nursing ethics in this time of crisis, con-
flict, and complexity, where journeying toward a moral horizon requires acute sensitivity to individual and collective differences, humility to listen to and learn from others and, critically, clarity regarding the nature of the horizon one is travelling toward.

The aspiration, detailed in the Conclusion chapter, to “promote ethical fitness and to provide hope for all of us in the nursing profession” is laudable and heartening. So, too, the authors hope that readers will “step boldly into shaping the future of health care” and “make ethical and political choices knowingly and wisely.” The authors’ confidence that the practice, scholarship, and political action of nurses will lead to a future where health becomes a reality for “all people on our planet” is confidence that nurses and advanced practice nurse leaders need to commit to and share. If nurse leaders, other nurses, and students of nursing lack the will and capability to shape the future, to redress health inequities, and to challenge social injustice, much-needed change will not occur. This reminds readers that nurses everywhere need to commit to caring always, abandoning never, and advocating courageously for all in need of health and social care.

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Endnotes

1 See Salem Witch Museum. (n.d.).
Dr. Rosalie Starzomski

Dr. Rosalie Starzomski is a professor emeritus at the University of Victoria School of Nursing. She is a graduate of Dalhousie University with a Bachelor of Nursing (1978), the University of Calgary with a Master of Nursing (1984), and the University of British Columbia (UBC) with a Doctor of Philosophy (PhD) in Nursing (1997). Her research, practice, teaching, and publications are focused on health care and nursing ethics, organ donation and transplantation, nephrology, biotechnology, end-of-life care, and advanced nursing practice. Dr. Starzomski has received a number of research grants from provincial and national organizations for her scholarly work and is co-editor of three editions of the book Toward a Moral Horizon: Nursing Ethics for Leadership and Practice. She has a longstanding interest in science fiction and the many ethical issues illuminated within that genre—issues often relevant for nurses and other health care providers when facing the rapid implementation of new technological developments into the health care system.

In 1984, Dr. Starzomski was the first advanced practice nurse at the Vancouver General Hospital, and, as a clinical nurse specialist in nephrology and transplantation, she worked with a variety of interdisciplinary teams in her areas of practice. For a number of years, she was an ethics consultant at the Vancouver Coastal Health Authority and was committee chair for several ethics committees.
In addition to her teaching at the University of Victoria School of Nursing, Dr. Starzomski has held a number of leadership positions, including associate director for the Lower Mainland campus, associate director for research and scholarship, and coordinator of the Advanced Practice Leadership Master's option.

Throughout her career, Dr. Starzomski has played an active role in health care policy development and has contributed to provincial, national, and international committees and task forces for organizations such as Canuck Place, the Kidney Foundation of Canada, the Canadian Nurses Association, the Canadian Council for Donation and Transplantation, and the World Council for Renal Care. Dr. Starzomski has been a member of Health Canada’s Expert Advisory Committee on Xenograft Regulation, the Canadian Institute for Health Information Organ Replacement Register, the Canadian Institutes of Health Research Standing Committee on Ethics, and the BC Ministry of Health Provincial Forum for Clinical Ethics Support and Coordination. She has been the recipient of a number of awards, including an Award of Excellence for Nursing and an Award of Excellence for Nursing Practice, both from the Registered Nurses Association of British Columbia; the University of Victoria School of Nursing Award of Excellence for Nursing Education; the UBC School of Nursing Alumni Award of Distinction; and the Queen Elizabeth II Golden Jubilee Medal for outstanding and exemplary service to the community and to Canada. In 2017, Dr. Starzomski was named by the Canadian Nurses Association as one of 150 Canadian nurse innovators and champions in health care, in honour of the 150th anniversary of Confederation.
Dr. Janet (Jan) Storch

Dr. Janet (Jan) Storch is a professor emeritus at the University of Victoria School of Nursing. She earned her degrees from the University of Alberta: a Bachelor of Science in Nursing (1963), a Master of Health Services Administration (1977), and a Doctor of Philosophy (PhD) in Sociology (1987). Dr. Storch was a professor in the Health Services Administration program at the University of Alberta and developed and taught courses on the history and values of the Canadian health care system. From 1990 to 1996, Dr. Storch was dean of nursing at the University of Calgary, and from 1996 to 2001, she was director of the School of Nursing at the University of Victoria.

Dr. Storch has been a scholar in health care ethics and nursing ethics since the mid-1970s. In 1982, she published an influential book titled *Patients’ Rights: Ethical and Legal Issues in Health Care and Nursing*. In 1996, she was a Visiting Fellow (Bioethics) at the Kennedy Institute of Ethics at Georgetown University in Washington, DC. During her career, Dr. Storch received research funding from several provincial and national health funding bodies. She has served as president of the Canadian Bioethics Society, president of the National Council on Ethics in Human Research, and was the chair of the Research Ethics Board of Health Canada and the Public Health Agency of Canada. From 1999 to 2019, Dr. Storch served on the US-based Western Institutional Review Board. She continues to publish articles, chapters, and books related to health care and nursing ethics, and has been co-editor of three editions of *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice*.

Dr. Storch led three revisions of the Canadian Nurses Association’s (CNA) *Code of Ethics for Registered Nurses* (in 2002, 2008, and, most recently, in 2017), and she served as scholar in residence at the CNA in 2001–2002. Dr. Storch was a founding
member of one of the earliest ethics centres in Canada, the John Dossetor Health Ethics Centre, established in 1985 at the University of Alberta. From 1992 to 1996, Dr. Storch served as chair of the Alberta Health Provincial Health Ethics Network Steering Committee. She has been a member of several ethics committees, including the Mount St. Mary’s Hospital (Victoria, BC) ethics committee as well as the Regional Ethics Committee, Vancouver Island Health Authority, and the BC Ministry of Health Provincial Forum for Clinical Ethics Support and Coordination.

Dr. Storch has been honoured by several provincial and national nursing associations and Canadian universities. She was the recipient of the 1982 Alberta Association of Registered Nurses Abe Miller Memorial Nurse of the Year Award; the Registered Nurses Association of British Columbia Award of Distinction; and the Canadian Association of Schools of Nursing Ethel Johns Award (given in recognition of distinguished service to nursing education in Canada). Dr. Storch has received an Alumni Honour Award from the University of Alberta, an honorary Doctor of Science from Ryerson University, and an honorary doctorate (Doctorem in Legibus) from the University of Western Ontario.
Dr. Patricia (Paddy) Rodney

Dr. Patricia (Paddy) Rodney is an associate professor emeritus at the University of British Columbia (UBC) School of Nursing. She holds a Bachelor of Science in Nursing from the University of Alberta (1977); a Master of Science in Nursing from UBC (1988); and a Doctor of Philosophy (PhD) in Nursing from UBC (1997). She is a co-editor of three editions of the book *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice*.

Dr. Rodney worked in critical care nursing at St. Paul’s Hospital, where she had the opportunity to learn about—and later teach in—a rapidly evolving area of clinical nursing practice. She came face to face with ethical challenges regarding end-of-life decision making for patients and their families, and witnessed the moral distress experienced by nurses and other health care providers. This fostered her lifelong interest in nursing ethics and health care ethics.

From 2007 to 2009, Dr. Rodney served as president of the Canadian Bioethics Society. She was also a founding board member of the Association of Registered Nurses of British Columbia and has consulted widely in the area of nursing ethics. She has had a long-standing research and teaching focus on understanding and addressing the moral distress of health care providers and the moral climate of health care delivery. During her career, Dr. Rodney has worked with practice-based research colleagues on diverse research initiatives to address these topics, as well as related policy challenges in health care delivery. She has also worked extensively in nursing education—teaching leadership, ethics, policy, and relational practice in the undergraduate and graduate nursing programs at the University of Victoria and UBC.

Dr. Rodney has been committed to influencing health care policy and was a member of a British Columbia panel on cardiac health. From 2016 to 2018, she was an expert member of a Canadian
panel on medical assistance in dying. She has been a member of
ethics committees in British Columbia and has served on the BC
Ministry of Health Provincial Forum for Clinical Ethics Support
and Coordination.

Dr. Rodney has received a number of awards for her scholarly
work, including an Award of Excellence for Nursing from the Xi Eta
chapter of Sigma Theta Tau and an Award of Distinction from the
College of Registered Nurses Association of British Columbia. In
2014, she received the Canadian Bioethics Society Distinguished
Services Award for her work in health care ethics. Dr. Rodney was
awarded the Dean’s Medal of Distinction by the UBC Faculty of
Applied Science in 2021 for bringing high honour to the faculty
through her contributions to the advancement of its vision, mission,
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Jan thanks her husband, Don Storch, who supported her as she worked on the three editions of this book. His patience, kindness, and unfailing encouragement was key to the success of this work. She thanks her three children, David, Michael, and Jolan, whose long-distance inspiration from Toronto, China, and Calgary was invaluable. Finally, Jan thanks her parents, Emma and Reiny Hennig, for their strong support throughout her career; and Dr. Shirley Stinson, whose counsel and commitment to nursing ethics and to graduate students was a major influence on Jan’s career.

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Rosalie Starzomski, Janet (Jan) L. Storch and Patricia (Paddy) Rodney
INTRODUCTION

The Moral Terrain

Rosalie Starzomski, Janet L. Storch, and Patricia Rodney

“Nursing ethics is concerned with how broad societal issues affect health and well-being. This means that nurses endeavour to maintain an awareness of aspects of social justice that affect the social determinants of health and well-being and to advocate for improvements.” (Canadian Nurses Association, 2017, p. 3)
collaboration, coalitions and, ultimately, strong moral communities. Creating this book is part of providing the knowledge required to continue to build moral communities within nursing and health care systems to enhance health care delivery.

Our purpose in revising this book is to highlight and celebrate the significant progression of nursing ethics in the face of rapidly evolving Canadian and global health care challenges. These challenges have been exacerbated by a worldwide SARS-CoV-2 pandemic, as well as significant resource constraints in Canada and around the globe. Our intent is to enhance the ability of nurses, including advanced practice nurse leaders, graduate students, and senior undergraduate students, to fully understand and enact the ethical dimensions of their practice. Overall, our goal is to promote leadership in nursing, in nursing ethics, for nursing and for nursing ethics.

In 2004 and 2013, we developed the first two editions of this book to serve as textbooks for graduate courses in nursing ethics and to provide practicing nurses with content to enhance their roles as leaders within diverse health care settings. We have had the opportunity to use the first two editions to help educate graduate nursing students, practicing nurses, and colleagues in other health care disciplines. We learned a great deal in the development and use of these first two editions. We thank our contributors, reviewers, colleagues, and students past and present for adding to our understanding of what is needed in this new, third edition.

In this edition of our textbook, we take up and continue to address the challenges that informed our 2013 second edition. That is, we “stretch our moral reasoning about the practice of nursing and health care and [also] challenge each nurse’s everyday moral activities, what we value, how we make decisions and behave, and who we are becoming by virtue of our moral choices.” And we continue to “challenge [our] readers to make ethical fitness in service of benefiting others [a] goal and offer incomparable resources to achieve this goal” (Taylor, 2013, p. xi).

It has been our commitment to these collective challenges, together with ongoing feedback from students and other colleagues, that has led to the planning, designing, and delivery of this book. Although the third edition is written for the audience we highlighted above, it is also relevant for other HCPs, as we work
together to develop strong moral communities and effective interprofessional practice models that result in quality patient care.

Readers of our previous editions will note that there is considerable new content in this edition of our book, particularly in relation to neoliberalism, social justice and equity in health care, Indigenous ethics and perspectives, decolonization of nursing and health care, ethnocultural contexts, racism, ethical concerns during pandemics, new technological developments, and the future of nursing ethics. Throughout the text, we aim for sequence, continuity, and integration in the diverse content areas that are discussed, in order to enhance understanding of the issues and provide learning opportunities for readers.

Our key goal is to enable nurses and other HCPs to become ethically fit (Kidder, 2009), to maintain ethical fitness, and to continue to push the boundaries of nursing ethics forward. Ethical concerns have continued to change over the decades since 2004 when our first book was published. Nurses have made great strides toward enhancing their ethical practice to uphold their commitment to the people in their care. We know that other HCPs, including physicians, social workers, and many other colleagues, are also concerned about ethical leadership and practice. Nurses have been instrumental in enlarging the focus on improving health and health care practice, and going beyond what has been considered the purview of traditional health care ethics and nursing ethics. Nurses have responded to the rapidly changing context of health care delivery and nursing practice, which includes an aging population, technological change, and a growing emphasis among health care organizations on a neoliberal ideology. These changes in context will be addressed by authors in the various chapters in this book.

Our focus for this text is based on our own research and engagement in ethics work in health care and nursing. We have noted that the moral well-being of nurses, and all HCPs, matters. As Doherty and Purtilo (2016) suggest, professional morality entails a strong commitment to “moral values, duty, and character” (p. 12). When sustained and shared, this commitment can help to create a moral community, where values are made clear, and where nurses can feel safe and heard when engaging in ethical action (CNA, 2017). While the well-being and subsequent practice of nurses is con-
tingent on such a sense of moral community within a positive moral climate overall, the patients for whom nurses provide care also require a sense of safety and community. This is particularly important if patients have been marginalized through negative experiences, such as racialization (Garneau et al., 2017).

Throughout this book, we highlight the need for leadership in health care ethics and nursing ethics. We believe that leadership for ethical policy and practice arises from nurses in senior leadership positions, from nurses in practice and from academics, all working in collaboration, each contributing within the limitations of their own contexts, but bringing unique knowledge, skills and energy essential to the provision of ethical nursing practice. (Storch et al., 2009, p. 78)

It is our hope that this text, while focusing primarily on nursing and nursing ethics, will also be informative for our colleagues in a variety of health care roles (including, for example, chaplains, dietitians, physicians, rehabilitation therapists, and social workers). We know that these colleagues are also concerned about and committed to fostering ethical leadership and practice. We also know that the expertise of nurses and all HCPs is required in order to promote effective health care delivery within a robust and ethical health care system.

Approach to the Textbook

We are using a new approach for this edited textbook, moving away from a print edition to a digital version of the book that will be accessible to all readers on an open access digital platform and downloadable to devices for offline reading. With the help of our colleagues at the University of Victoria Libraries, we are ensuring that access to this book, and resources related to it, will be available to all who are interested in reading and using the content in their educational programs and practice settings.

We have divided the book into three sections:
1. **Section One**: Mapping the Moral Climate for Health Care and Nursing Ethics

2. **Section Two**: Pursuing Equity in Diverse Populations

3. **Section Three**: Navigating Horizons for Health Care and Nursing Ethics

As described below, the authors of the chapters in each section provide an overview of the current context in specific areas, and also provide recommendations for future changes. A number of chapters are entirely new; however, some authors have drawn on and updated content from their chapters in previous editions of the book. In all of the chapters, the authors use inclusive language to ensure that the diverse populations within communities are represented. In each chapter, “Ethics in Practice” scenarios are provided to illustrate the manner in which ethics is an integral part of practice in all health care settings, as well as in policy development, education, administration, and research. In the case scenarios, authors address ethical challenges, including those faced by Indigenous communities, ethnoculturally diverse communities, and marginalized communities. As mentioned earlier, in each chapter of the book, readers will have an opportunity to consider ethical concerns from local to global levels. “Questions for Reflection” are also provided at the end of each chapter, along with key references for the continued exploration of ethics in leadership and practice.

**Section One: Mapping the Moral Climate for Health Care and Nursing Ethics**

The first section in the book includes seven chapters, most new to this edition, and others significantly updated and revised. The content of the chapters in this section is related to situating nursing ethics both historically and within the current health care environment, focusing on moral agency and moral climate, along with a rich approach to theory in practice. The authors of the chapters focus on the theoretical development and foundations of nursing ethics, pointing to further developments in the chapters that follow.
In Chapter 1, the authors provide theoretical perspectives about nursing ethics to aid each nurse to develop a moral compass for leadership. The authors acknowledge and discuss a distinct nursing ethic, the importance of relational practice, and the need to use a justice and equity lens in nursing. They provide an historical sketch of the development of nursing ethics in order to describe current philosophical and ethical thinking in nursing; to critically examine ethical principles and theories (including foundational theories such as feminist ethics and relational ethics); and to focus on concepts of ethical practice, specifically moral agency and moral climate. The authors explore two ethical decision-making frameworks and a duty to care guideline. In addition, they provide opportunities to use these resources in Ethics in Practice case scenarios.

Moving to Chapter 2, the authors review research ethics to highlight selected historical research ethics abuses in Canada and worldwide. Many of these situations involved nurses. These human rights abuses led to the development of research ethics guidelines in numerous reports; for example, the Belmont Report from the United States, in which three key principles—respect for persons, beneficence, and justice—were emphasized. In Canada, the Tri-Council Policy Statement (TCPS 2) guidelines for research ethics were developed, focusing on respect for persons, concern for welfare, and justice. The current use of research ethics boards (REBs) and examples of research ethics guidelines and practices for Canadian nurses are highlighted in this chapter.

In Chapter 3, the authors discuss and critique Canadian health care delivery. They begin with a focus on the manner in which health care delivery is structured in Canada, including attention to federal, territorial, and provincial responsibilities. They emphasize that the mode of health care delivery cannot be described as a “health care system” because it is actually thirteen health care systems, located in ten provinces and three territories. They highlight that a former premier of Saskatchewan, Tommy Douglas, led the way for changes in health care delivery with his belief that health care was a right of all citizens. The authors provide both a history of the division of health care roles, as well as a discussion about the challenges of funding health care. Current health care deficiencies are noted, including limitations in long-term care,
mental health care, and care for Indigenous people. The authors end the chapter by stressing the need for nurses to practice using a social justice perspective to foster equitable health care delivery.

In Chapter 4, the author builds on an analysis of public health (PH) ethics from previous editions of this textbook in describing its development over recent decades. The author highlights how PH ethics differs from health care ethics and how it has been implemented in nursing. Current PH ethics issues are presented, including a discussion of PH research ethics, as well as environmental and global ethics. Ethical challenges related to pandemics are discussed, and ethical decision-making frameworks for pandemics are reviewed. The author concludes the chapter with a summary of key developments in PH ethics and a discussion about PH issues for the future.

Chapter 5 is a unique contribution to this textbook from a number of Indigenous scholars in nursing. They use circle pedagogy to explore together what nursing ethics means from their own First Nations and Métis perspectives. With their distinction-based approach, they acknowledge the rights and lived experiences of First Nations, Inuit, and Métis people as unique. In order to convey the richness of their dialogue, their circle is provided in video format, and a transcript of the video is also included.

In Chapter 6, the authors provide a definition of moral distress and examine the basic assumptions underlying the definition, differentiating it from other related concepts. They highlight the importance of moral reasoning and moral action of nurses as foundational for the prevention of and responses to moral challenges in their practice. The authors explore situations where nurses and other HCPs experience moral distress. In addition, they provide recommendations for advanced practice nurse leaders at individual (micro), organizational (meso), and larger system (macro) levels of the health care system to improve the moral climate of health care practice environments. They conclude the chapter by highlighting the importance of moral leadership in fostering ethical practice environments.

The authors of Chapter 7 address nursing ethics and leadership for advanced practice nursing. They focus on the interface of the nursing profession with current systems and organizations, noting
that this interface is foundational to enacting ethical leadership in any context. Current concepts of ethical leadership are deconstructed and reconceptualized in light of calls to action in current health systems and public policy. Several ethical leadership models and frameworks are presented and critiqued. The authors close the chapter with recommendations to rejuvenate the voices, power, and political influence of nurses.

Section Two: Pursuing Equity in Diverse Populations

The authors of the nine chapters in this section of the text address diverse patient populations and practice arenas. Topics include nursing education, nursing practice, mental health care, childbearing individuals and families, children, home health care, people with disabilities, older adults, and palliative care at the end of life. While the substantive content regarding challenges and practice interventions differs for each chapter, the authors share a common focus on two foundational and interrelated concepts to support ethical practice—equity and diversity.2

In the first chapter in this section, Chapter 8, the focus is on becoming a transformative nurse educator through using a relational pedagogy. This is a perspective which nurse educators use to prioritize relationships over individualism. The authors focus on nursing education as an ethical practice grounded in principles of social justice; safe, competent practice; and relational pedagogy. They include “A Framework for Ethical Decision Making in Nursing Education” that provides guidelines to actualize key principles in higher education. By focusing on nursing education as an ethical practice, and providing a comprehensive ethics resource, the authors have created a chapter for both new and experienced nurse educators.

In Chapter 9, the authors describe the importance of health equity as being crucial across all levels of health care delivery. They provide an argument for why and how equity ought to be promoted in health care practice. They explore foundational concepts such as the social determinants of health, health equity, and critical social justice. The authors claim that health equity is fundamentally an ethical concept, and warn that there is little critical analysis or
application of the concept in practice. They point to power imbalances and structural and systemic conditions that create inequities. In closing, they suggest proactive strategies to promote health equity, including fundamentally shifting and redistributing power, and addressing challenges in order to shift organizations and systems toward equity, particularly when racism is involved.

In Chapter 10, the authors begin by addressing the significant prevalence of mental health and substance use issues in Canada, particularly for those in the lowest income groups. They provide a comprehensive account of how stigma, economic challenges, and limited access result in serious inequities in mental health care delivery. Drawing on their own clinical expertise in mental health care, and their comprehensive analyses of historical trends and initiatives, the authors point to how effective advocacy and leadership by nurses can promote more equitable access to mental health care. In an appendix, they provide readers with online resources about mental health care delivery.

The authors of Chapter 11 emphasize the importance of choice and control in the birth experiences of childbearing individuals, including those who identify as gender diverse. They describe how nurses have a social justice mandate to advance reproductive health policy and practice in partnership with childbearing individuals and families. Drawing on a report by a World Health Organization commission on the social determinants of health, the authors argue for a social justice vision to achieve health equity through safe, ethical, and effective nursing care for childbearing individuals and families. They emphasize that advancing equity of access to reproductive health care is a prerequisite to nurses being able to meet their moral obligations and ethical values in various practice settings—including acute care settings and urban and rural community settings.

The author of Chapter 12 builds on insights from clinical practice, and underscores the importance of nurses listening to children, and not just treating them. The chapter begins with a discussion about the need for nurses to attend genuinely to the moral voices of children, while also recognizing limits to how much responsibility can be safely accorded to them. Drawing on seven related practice scenarios that are based on the author’s clinical experiences, illus-
trations are provided to show how advanced practice nurse leaders and other HCPs can better support the moral agency of children.

The authors of Chapter 13 point to the need for appropriate resources for home health care in Canada and address implications of current home care policy, offering recommendations where they challenge neoliberal values and beliefs to inform the work of nurses in diverse roles. They warn that Indigenous communities are particularly vulnerable to inequities in the quality and availability of home care, especially in rural, remote, and northern locations. Further, they describe the resulting widespread off-loading of responsibilities for care, and the impacts of this on patients, families, and home care workers. The authors conclude by warning that systemic problems in the delivery of home care negatively affect the health and well-being of those receiving care and their caregivers. In addition, they provide suggestions about how advanced practice nurse leaders can be involved in influencing change in home health care.

In Chapter 14, the authors describe the stigma, exclusion, and discrimination that disabled people experience when accessing health care. They explain that how people think about disability affects the way disabled people are treated in the health care system. They summarize conceptual models of disability and provide a comprehensive overview of the language related to disability, explaining why language is critically important. The authors also offer directions for systems-level changes, and emphasize that leadership in nursing practice for the care of disabled people requires both education and knowledge to address biased health care practices.

The authors of Chapter 15 begin by emphasizing how the COVID-19 pandemic shed light on the limitations of Canada’s long-term care system. They provide an account of the health and illness challenges older adults face, including the impacts of the social determinants of health, ageism, and the limitations of current systems of care. In their analyses, they illustrate fault lines in resources for older adults living at home, in the community, and in long-term care settings. They articulate a new vision for healthy aging, and provide content regarding ethical leadership and improving attitudes toward aging. This latter section is focused on ways for nurses and other HCPs to improve the well-being of older adults.
The authors of Chapter 16 begin by asking readers to consider their own potential death. They provide information about suffering in end-of-life care, and challenge readers to critically examine the assumption that the alleviation of suffering is invariably a moral good. The authors stress that justice and dignity are the key principles of a palliative care ethic, and draw attention to the role of these principles when nurses are caring for gender diverse people at the end of life. They subsequently discuss the ethical challenges and leadership implications of medical assistance in dying (MAiD) for nurses and their patients. The authors conclude the chapter by noting that advanced practice nurse leaders are key in advocating for policy change to ensure that the appropriate structures and systems are available for quality end-of-life care.

Section Three: Navigating Horizons for Health Care and Nursing Ethics

In section three of the textbook, which includes five chapters, we expand and broaden our horizons to focus discussion on genetics and identity, health informatics, biotechnology, and global health. We conclude this section, and the textbook, with a chapter where the editors imagine the yet-to-be-explored areas of nursing ethics, and provide final reflections about future horizons in nursing ethics and ways to move boldly forward.

In Chapter 17, the authors write about genetics and identity. They begin the chapter with a discussion of a number of genetic and genomic tools used in health care settings. Using a feminist and relational perspective, they discuss the complex ethical concerns that arise when analyzing and interpreting genetic findings. They move on to describe and analyze a number of ethical issues in genetics relevant to nurses and advanced practice nurse leaders, such as informed consent, incidental genetic findings, and access to genetic technologies. They conclude the chapter by highlighting the key role that advanced practice nurse leaders have in contributing to shaping the future of genetic and genomic technologies within health care systems.

As part of Chapter 18, experts in nursing ethics, technology, and health informatics participate in a Zoom discussion about a
number of ethical considerations, including privacy, confidentiality, and safety; use of electronic health records; virtual care; and the use of artificial intelligence when providing health care. The speakers emphasize that there is a need for nurses in leadership positions in practice, education, administration, and research settings who can advocate for the suitable use of technology that meets the needs of patients, families, and communities. They articulate a vision for nurses where the profession as a whole can be more purposefully involved in evaluating, responding to, and helping shape the future of the technological and digital world in health care. The Zoom video of the session is included as part of the chapter, as is a transcript of the discussion.

In Chapter 19, the author emphasizes that the twenty-first century is often called the century of biotechnology. In this chapter, xenotransplantation is used as an exemplar of biotechnological development. A number of ethical and societal challenges, often pushed to the margins, are explored as nurses and other HCPs “boldly go where no one has gone before.” Many of the issues, concerns, and troublesome questions that emerge in the debate about whether xenotransplantation is part of the therapeutic armamentarium to treat end-stage organ failure are discussed; a number of these concerns are also evident in other domains of biotechnological development. The author describes approaches to encourage public participation in health care decision making and advances the dialogue about the ethical and societal concerns regarding biotechnology. In concluding the chapter, the author offers strategies to enhance advanced practice nurse leadership in the area of biotechnology.

Global health ethical issues are explored in Chapter 20. The author provides advanced practice nurse leaders with key concepts that are significant in global health, discusses values related to global health, and describes the interface of global health with human rights. One highlight of this chapter is a discussion of SARS-CoV-2, and how this global viral threat has made global interconnectedness so evident. The author challenges readers to consider how to cultivate the moral courage to live together harmoniously. The chapter concludes with an overview of ethical
responsibilities for advanced practice nurse leaders in their roles as ethical global citizens.

Conclusion

In this chapter, we provided an overall description of the textbook, as a road map for readers to follow as they engage with the content throughout the book. We highlighted that nurses face a myriad of challenges as they try to uphold the ethical standards of the profession in increasingly constrained practice environments. We also described how nurses are in unique positions to promote social justice and equity in health care due to the level of trust and interaction they have with patients, families, and communities.

We noted that the nursing profession is in urgent need of greater numbers of advanced practice nurse leaders who have expertise in ethics, and who can drive inquiry forward in nursing ethics. We need leadership in ethics throughout every facet of our profession, and we need leaders who can support the ethical practice of our colleagues in other disciplines. This book is meant to provide support for such leadership. We encourage readers, as they engage with the discussions and questions in the chapters, to consider ethical reflection as both a lens and a mirror—that is, we can use ethics not only as a microscope, but also as a telescope, helping us to envision what is needed for the future.
**Endnotes**

1. We use the term advanced practice nurse leaders throughout the book to include registered nurses who have graduate preparation in nursing. Advanced practice nurse leaders have roles within the health care system where they are involved in supporting and strengthening nursing practice; educating students, nurses, patients, families, and communities; advocating for patients, families and communities; and influencing change in health care systems.

2. As authors and editors of this text, we consider equity to mean supporting persons according to their needs and resources, and treating like situations alike. We understand respecting diversity to mean being open to, learning from, and supporting people equally, regardless of diverse attributes such as age, ethnicity, language fluency, gender identity, and socio-economic status.

**References**


SECTION 1

Mapping the Moral Climate for Health Care and Nursing Ethics
NURSES HAVE THE RESPONSIBILITY TO ENSURE that their practice is not only technically and clinically competent, but also ethical. At the heart of ethical practice in any field is understanding what is happening, what ought to happen, and how to navigate the difference. Many of these responsibilities are articulated in professional codes of ethics, standards for nursing practice, and health care regulatory guidelines.

The focus of advanced practice nurse leaders on ethics in health care has not been consistently visible. For example, a leading...
American nursing ethics scholar, Marsha Fowler, (2017) published a philosophical paper called “Why the History of Nursing Ethics Matters,” arguing for the importance of nursing’s unique ethical heritage, and the need for preservation of that history. With Fowler’s insights in mind, our premise throughout this chapter—and this book overall—is that for advanced practice nurse leaders, other nurses, and health care providers (HCPs), ethical action necessitates moving toward “the oughts” of ethical practice. This is true for ethical action that takes place for individuals, families, communities, and larger systems at local, provincial, and national levels.

A key element of ethics for advanced practice nurse leaders is social justice. Drawing on the work of Iris Marion Young (1990), social justice means understanding and addressing how members of communities experience oppression in different ways as a result of structural inequities. A multi-layered approach by nurses can avoid an otherwise narrow focus on individuals when socio-political contexts, such as poverty and immigration experiences, are ignored. Canadian nursing policy expert Michael Villeneuve (2017) warned that “politically, the [nursing] profession punches below its weight,” and that our “country is worse for it” (p. ix). Advanced practice nurse leaders in Canada are well positioned to increase their support for individuals, families, and communities; therefore, we have written this chapter to support the ethical practice of these nurse leaders.

Our intent in this chapter is to foster a relational understanding of persons, whereby we acknowledge that people are located in unique and multi-faceted socio-political and cultural contexts (Hartrick, Doane & Varcoe, 2007). We adopt a relational understanding of social justice for nursing leaders as we consider moral philosophies of social justice and ethics of care. Leading Canadian ethicists describe a relational approach to ethics as including mutual respect, engagement, and embodied knowledge (Bergum & Dossetor, 2005). Relational ethics provides a means of attending to inequities experienced by people related to privilege and discrimination, which impair their health (Baylis et al., 2008). An ethical goal of nurses in advanced practice roles is to understand, and ultimately address, the cumulative effects of inequities at individual (micro), organizational (meso), and larger societal
(macro) levels, particularly for those who are marginalized, or who are at risk of being marginalized.

In what follows, we focus on ethical theory and practice in health care and nursing. In doing so, we provide a brief review of the history of health care ethics, relational ethics, and nursing ethics. We commence by summarizing the evolution of health care ethics. We then address the concomitant evolution of nursing ethics, including how nursing ethics is informed by a critical social justice perspective. This perspective includes *intraprofessional* and *interprofessional* practice and collaboration, ethical leadership, and relational practice. An exploration of related areas of ethical skill development for advanced practice nurse leaders—specifically in regard to ethical decision making—is included. This review is not meant to be exhaustive, as many theoretical perspectives are expanded and integrated in other chapters of this book.

In the latter part of this chapter, we include ethical decision-making frameworks and four case scenarios to assist readers to apply ethical analyses, develop their ethical decision-making and consultation skills, and generate related recommendations for action at the micro, meso, and macro levels of the health care system. We highlight the importance of promoting social justice for individuals, groups, and communities in the ongoing development and application of nursing ethics in Canada. By focusing on social justice, we join colleagues who have, over time, warned that inequities in access to appropriate resources lead to serious disparities in the lives of many people (Anderson et al., 2009; Clark & O’Mahony, 2021; Fraser, 1999, 2001; Young, 1990).

**A Brief Overview of Health Care Ethics**

For nurses and other HCPs to effectively engage in ethical practice that fosters the health and well-being of patients, families, and communities, they need to analyze and apply the beliefs and values that underpin their practice, including the values-based theories they use (Rodney et al., 2013). As Canadian ethicist Michael Yeo (2020a) reminds us, it is important for HCPs to appreciate and understand *ethics*, where the focus is on theories of right and wrong, and includes normative standards for conduct (Fry & Johnstone,
It is also important for HCPs to appreciate and understand *morality*, where the focus is more specifically on the moral ideals of individuals and their judgments about what *ought* to happen in particular circumstances and contexts (Yeo, 2020b). HCPs enact morality in personal, societal, and group practice contexts (Doherty & Purtilo, 2016).

The study and application of ethics and morality have long and multi-faceted histories, which have been influenced over time by societal change and theoretical developments in philosophy and theology. HCPs have incorporated these developments into their practice to help determine their most appropriate moral actions in challenging clinical circumstances (Rodney et al., 2013). The application of ethical theory continues to help HCPs to “systematize moral intuitions, values, and principles in a consistent framework or to root them in a common ground” (Yeo, 2020b, p. 39). In so doing, such theory helps HCPs to enact what Yeo refers to as the “oughtness” of health care practice—that is, to consistently work towards values-based goals.

Some ethical theories that have particularly influenced the development of contemporary health care ethics include *deontology*—acting in a manner that universally focuses on the well-being of the individuals involved; *utilitarianism*—focusing on the practical effectiveness and consequences of actions and policies; and *contractarianism*—promoting fair distribution of goods and services, particularly for those who are in need (Rodney et al., 2013).

Other theoretical perspectives relevant to ethics include virtue theory, natural law, and human rights. *Virtue theory* was strongly influenced by philosopher Aristotle and theologian Thomas Aquinas. Virtue theory can assist HCPs to reflect on and enact virtues in living a moral life (Rodney et al., 2013). *Natural law* is an approach society has inherited from theology, and provides moral guidance in accordance with theological approaches to understanding and acting on rationality and nature (Rodney et al.). *Human rights* are often addressed in Western societal discourse and constrain powerful individuals from overriding certain interests of less powerful individuals. Legal theorists in particular are known for contributing to the articulation and actualization of human rights (Rodney et al.). Further, human rights are foundational to research ethics, where
there must be a significant focus on protecting the rights of patients and research subjects (Sherwin, 2011).

Notwithstanding the evolution in the development and application of ethical theory noted above, it is also important for nurses to pay attention to a caution from Fowler (2017), who suggested that the rapid and enthusiastic adoption of ethical theory from other disciplines risked overshadowing the moral identity of nurses. Fowler further warned that as nurses share ethical insights and progress with colleagues in other health care disciplines, they ought to be clear about the unique ethical history and identity of nursing. This history and identity entail a significant focus on social justice, including addressing oppression in society (Clark & O’Mahony, 2021). As authors of this chapter, we believe that advanced practice nurse leaders are well positioned to study, apply, and further develop ethical theory for nurses.

The Development of Nursing Ethics as a Field of Inquiry

As the field of health care ethics has evolved, so too has the field of nursing ethics. In what follows, we highlight the contributions of several of the early nurse theorists in ethics. We acknowledge that this is not an exhaustive review of all the contributors to the field of nursing ethics, in North America or worldwide.

One early contributor to the field of nursing ethics was Virginia Henderson, from the United States (US), who, in her groundbreaking 1966 book, *The Nature of Nursing: A Definition and Its Implications for Practice, Research and Education*, articulated that human needs were the central focus of nursing practice, and that nurses should care for patients until they could care for themselves. In her words, “patient care should be individualized … the nurse will seek constantly to help the patient meet [their] needs and live as normally as possible” (p. 31). It is our belief that Henderson’s articulation of the nature of nursing helped to create an understanding of what nursing ethics ought to entail.

As nurse theorists continued to explore and write about nursing theory, it became clear that direction for ethical nursing practice was also required. In 1980, a Canadian pioneer in nursing ethics, Sister M.

In 1982, Janet Storch, one of the authors of this chapter, wrote a book entitled *Patients’ Rights: Ethical and Legal Issues in Health Care and Nursing* (1982). This was one of the first books written by a nurse ethicist in Canada. In it, Storch described the role of nurses and other HCPs concerning patients’ rights. She spelled out what the expectations should be for all nurses and people in care, based upon what were envisioned as consumer rights of the day; for example, the rights to be informed, to be respected, to participate in decision making, and to have equal access to care.

Another nurse scholar who led the way in developing nursing ethics was Sara T. Fry from the US. In the early days of nursing ethics as a field of study, she sought to differentiate nursing ethics from the rapidly evolving work in medical ethics and health care ethics, noting that the evolution of nursing ethics was initially too dependent on theories of medical ethics (1989). Fry built on the work of other nurse scholars who were addressing nursing ethics, and included perspectives from feminist theorists, such as Gilligan (1982) and Noddings (1984), as well as the perspectives of physician ethicist Pellegrino and philosopher Thomasma (1988). Fry argued that instead of relying solely on contemporary theories of medical ethics, the nursing profession ought to focus on caring as a core ethical value. In addition, she claimed that caring must be grounded by focusing on people rather than on abstract and idealized notions of moral actions. It is important to note that over time, Fry’s theorizing about nursing has had a significant impact on the evolution of nursing ethics. She inspired nurses, including some of the authors of this chapter, to engage in scholarship regarding nursing ethics.

Another important contributor to the field of nursing ethics was Patricia Benner, from the US, who published a pivotal book titled *From Novice to Expert: Excellence and Power in Clinical Nursing Practice* (1990), where, based upon dialogue with nurses, she described how nurses acquire nursing knowledge, competence, and skill. Benner noted that too much attention had been given to role relationships and socialization in nursing practice and too little to
nursing ethics and actual nursing practice; that is, “the knowledge embedded in actual nursing practice, that accrues over time in the practice of an applied discipline” (p. 1).

Nursing research and scholarship related to nursing ethics have continued to evolve. In 1996, Verena Tschudin, a nurse from the United Kingdom, made a significant contribution to the nursing ethics world by founding the journal *Nursing Ethics: An International Journal for Health Care Professionals*. Tschudin also published the books *Deciding Ethically: A Practical Approach to Nursing Challenges* (1994) and *Nurses Matter: Reclaiming our Professional Identity* (1999). In her 1994 book, Tschudin provided ten cases based upon a range of principles, such as truth-telling, justice or fairness, and honesty, demonstrating approaches to their ethical resolution. In her 1999 book, she explicated the link between ethics and power, and how power is used. She used the approach of outlining, then discussing, what should matter in ethical practice.

Another nurse ethicist from the UK, Ann Gallagher, has contributed greatly to the evolution of nursing ethics. She became editor-in-chief of *Nursing Ethics: An International Journal for Health Care Professionals*, following in the footsteps of Verena Tschudin. Her writing and scholarship in the field of nursing ethics are clearly articulated and influential. For example, she has written about the state of nursing ethics and the role of the International Council of Nurses, and she has also written a number of editorials related to moving the field of nursing ethics forward. In one editorial, she made a major contribution when she focused on providing care during the COVID-19 pandemic, and described the experience of families separated from their loved ones during the pandemic (Gallagher, 2021).

Marsha Fowler, from the US, is another leader in nursing ethics. She has published extensively about ethics in nursing, religion in nursing, health disparities, and health policy in global health. She has written several editions of an important book about nursing ethics titled *Ethical Dilemmas in Nursing Practice* with co-authors Anne Davis and Mila Aroskar (Davis et al., 2010). She also published a book about religious ethics and nursing with three co-authors, Sheryl Reimer-Kirkham, Richard Sawatsky, and Elizabeth Johnston Taylor (Fowler et al., 2012). Her leadership in
nursing ethics has included working with the American Nurses Association (ANA) to develop material such as a *Guide to the Code of Ethics for Nursing: With Interpretive Statements: Development, Interpretation, and Application* (Fowler, 2015a) and a *Guide to Nursing’s Social Policy Statement: Understanding the Profession from Social Contract to Social Covenant* (Fowler, 2015b).

Writing by scholars about nursing ethics has proliferated, and nursing ethics texts, focused primarily on the education of undergraduate nursing students, have been developed. For example, in the US, authors such as Davis et al. (2010), Doherty and Purtiło (2016), and Fry and Johnstone (2008) have written textbooks that have been used widely. In Canada, Yeo et al. (2010, 2020c) have written a textbook that has been used extensively in undergraduate nursing programs. For graduate nursing students, Storch et al. (2004, 2013) developed and edited two previous editions of *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice*.

The development of nursing ethics has been enriched, as well, by colleagues in other professions. Nurse ethicist Vangie Bergum and physician ethicist John Dossetor wrote about relational ethics in their book titled *Relational Ethics: The Full Meaning of Respect* (2005). This book has had a significant impact on the evolution of relational approaches to ethics. Baylis (a philosopher), Kenny (a physician ethicist), and Sherwin (a philosopher) (Baylis et al., 2008) have individually and collectively written extensively about the theory and application of health care ethics. A particular focus of their collaborative work was on relational ethics, where they addressed ethical theory not just in abstract terms, but in terms of the relationships and power dynamics that constrain or foster individual and collective well-being.

As nursing scholarship about ethics, including the concept of caring, proliferated, thoughtful and constructive analyses of nursing ethics began to emerge. In 2004, nurse scholars Joan Liaschenko (from the US) and Elizabeth Peter (from Canada) co-wrote a paper discussing the limitations of contemporary understandings of nursing and nursing ethics, subsequently arguing for a conceptualization of nursing as work that profiles and analyzes the value of nursing’s intellectual and manual labour. In continuing their focus on what nurses ought to do, and how, Liaschenko and Peter, as well as other
nurse scholars such as Storch et al. (2013), focused on nurses as moral agents; that is, as individuals who have the capacity to recognize, deliberate, reflect, and act on moral responsibilities. Peter offered a thoughtful analysis of how nurses could foster social justice by working through a socially connected model of moral agency:

Because social justice concerns primarily social groups and their relative positioning, as opposed to individuals outside of group membership, a conceptualization of moral agency as a social or collective construct is useful in terms of thinking about effecting social change. (2011, p. 13)

Peter’s analysis is insightful and inspiring. Fabienne Peter (2004), a theorist from the United Kingdom writing on social justice, added the complementary insight that justice entails the premise that “to be able to pass a judgement on social inequalities in health, we need an understanding of the underlying causes” (p. 104). In other words, nurses ought to attend to the individuals they encounter in their practice, and pay attention to the wider relational contexts affecting those individuals. This broader view includes, for example, the familial, socio-political, and environmental strengths and challenges affecting all levels of context for individuals, families, and communities. A commitment to social justice is foundational to ethical nursing practice (Anderson et al., 2009), and is supported by a concomitant commitment to relational practice. Integral to these commitments is an understanding of human rights and social justice.

**Nursing Ethics: Human Rights and Social Justice**

Social justice is a concept that originated in philosophical discourse and is widely used across the social sciences and in ordinary language (Jost et al., 2010). The idea of social justice concerns a moral commitment to ensure that opportunities, resources, and privileges are fairly and equitably distributed between people within a society (Anderson et al., 2009; Cook et al., 2019). Nursing has a long history with roots in social justice work; in fact, the inclusion of broad social contexts and client-centred approaches
can be found across nursing’s various communities of practice, from institutional to community settings (Clark et al., 2015).

At the heart of nursing’s ethical commitment to social justice is the client, who is nested in a social and ecological environment. By considering social justice, nurses affirm a moral commitment to redress inequities and provide resources for health and health care access (Rodney et al., 2009). A growing body of research in nursing and the health sciences over the past decades has made it increasingly clear that social determinants of health have a major impact; yet social justice in nursing remains a work in progress (Anderson, 2009; Clark, 2015; Rodney et al.). For example, it is often unclear how codes of ethics can provide direction for nurses about social justice aims when they are making ethical decisions. Given the complexity of health care and structural vulnerabilities associated with systemic social exclusion, nurses need direction about social justice in order to foster a responsive health care system. This system should make space for nurses to take social action to help to redress systemic processes of exclusion directly affecting the health and well-being of communities and populations.

All nurses ought to have a mandate to enact their ethical commitment toward social justice. Advanced practice nurse leaders, including clinical nurse specialists and nurse practitioners, are in leadership roles where they are required to meet the complex health needs of Canadians in a wide variety of settings, and contribute to the development of a sustainable, efficient, and effective health care system (Canadian Nurses Association [CNA], 2017). From an advanced practice nursing perspective, the ethics of everyday practice is not devoid of social justice issues. Young (1990) has argued that oppression “is structural and occurs through systemic constraints on groups that are not necessarily the result of the intentions of a tyrant, rather … its causes are embedded in unquestioned habits, norms and symbols, in the assumptions underlying institutional rules and the collective consequences of those rules” (p. 41). Thus, advanced practice nurse leaders are uniquely positioned to mitigate not only the inequalities and inequities that pertain to their clients, whether they be patients, families, groups, or communities, but also the policies which sustain and underpin the root causes of health and health care inequities. In this sense,
social justice can be viewed as an ethical imperative that is not apolitical. It can be defined as a normative practice of “political accountability” (Clark et al., 2015).

**Diversity and Complexity**

Our world is increasingly divisive, based on longstanding national and international inequalities. These inequalities include increased health disparities and social inequities at the intersections of race/ethnicity, class, gender, (dis)abilities, and sexual identities, as well as systemic processes of social exclusion, racism, and human rights abuses. The people who experience the most health disparities are the structurally vulnerable; that is, people who experience social exclusion and oppression based on, for example, racism and classism. Vulnerable groups also experience more complex care needs and multiple morbidities, such as chronic illness, mental health concerns, addictions, and issues of poverty and homelessness (Stafford et al., 2017; Stajdhuhar et al., 2019). These inequalities have become more apparent as a result of the impact of COVID-19 and the subsequent challenges of accessing and delivering health care. Historically, structural inequalities have excluded access by social groups to resources that support their health and well-being. With input from a variety of stakeholders, there is a growing move in Canada to address such inequalities. This includes continuing to engage in a truth and reconciliation process where nurses and other HCPs can be part of addressing the social injustices experienced by the Indigenous Peoples of Canada.

**Equity**

One of the goals of social justice is to work towards equity. By equity, we refer to the policies and practices which take into consideration the social determinants of health, so that people who are structurally vulnerable can access and receive appropriate care. Political feminist scholars Iris Marion Young (1990) and Nancy Fraser (1999, 2001) have drawn attention to expanding the notions of justice and equity. They argued for not only a (re)distribution of social goods and services, but also for social justice, including the recognition of difference and the systemic exclusion of non-dominant groups in
policy decision making. Fraser highlighted the need to recognize differences between social groups, which is fundamental to the notion of equity.

Jost and colleagues (2010) delineated three broad sets of criteria for social justice as a potential framework for consideration: (a) benefits and burdens in society are dispersed in accordance with some allocation principle (or set of principles); (b) procedures, norms, and rules that govern political and other forms of decision making preserve the basic rights, liberties, and entitlements of individuals and groups; and (c) human beings (and perhaps other species) are treated with dignity and respect, not only by authorities but also by other relevant social actors, including fellow citizens. In order to operationalize nursing leadership in advanced practice settings, a relational approach across micro, meso, and macro levels could strengthen a socially just health care system. As was noted earlier in this chapter, nursing practices across these levels intersect and are interrelated.

Values of equality can be seen in the distribution of benefits and burdens in society. However, Young (1990), Fraser (1999, 2001), and Reimer-Kirkham and Browne (2006) suggested that a broader framework for understanding social justice needs to extend beyond a distributive justice paradigm. This requires an analysis of the root causes of social inequities. Reimer-Kirkham and Browne stated that “with associated marginalization, one begins to see sustained intergenerational patterns of ill health and human suffering not as examples of poor individual choices or flawed social communities, but as the results of diminished life opportunities that have systematically ... been denied through complex institutional policies” (p. 335). The challenges with distribution policy are evident when examining access to primary health care services, which are intended to be the first point of contact to the health care system. Under an ideal distribution model, it is assumed that everyone can access health care despite, for example, their education level, language, health literacy, gender, and socio-economic status. However, many communities remain without access to primary health care, based on that complex array of circumstances. Thus, distribution of benefits and burdens must reflect the differences and differential impacts of
health experienced within society, particularly the systemic exclusion of non-dominant groups (Clark & O’Mahony, 2021).

Advanced practice nurse leaders ought to consider caring as a moral imperative. Care ethics, as a political and moral philosophy, can provide a lens to examine values and practices associated with social justice and advanced practice nursing. Engster (2014) argued that “care is the other half of health care that has been almost completely ignored in normative discussion of health policy but provides the best reason […] to continue subsidizing comprehensive health-care services” (p. 156–157).

A focus on social justice should be taken up not only by individual nurses, but also by professional nursing associations. Indeed, the CNA (2017) highlighted that

Nursing ethics is concerned with how broad societal issues affect health and well-being. This means that nurses endeavour to maintain an awareness of aspects of social justice that affect the social determinants of health and well-being and to advocate for improvements. Although these elements are not part of nurses’ regulated responsibilities, they are part of ethical practice and are important educational and motivational tools for all nurses. (p. 3, emphasis in original)

The ethics of everyday practice requires a relational and intersectional approach, in which the everyday is not devoid of social determinants of health, and therefore, engaging in political action, advocacy, and reflexivity is also a necessary component of nursing ethics. Given that ethics is an everyday practice, nurses ought to engage in political decision making and action to preserve the basic rights of society and health.

Health care is a human right, and lack of access to it needs to be seen as a serious form of injustice. The CNA (2017) has emphasized that nurses ought to use their individual agency to promote justice. However, this framing is not sufficient for contemporary nursing practice, and may not be useful to address the intersecting social and political dimensions of health and illness in a complex health care system (Pauly & Storch, 2013). In this context, it remains a
moral imperative that advanced practice nurse leaders and nurses across all settings engage in collective reflexivity and advocacy. The CNA (2017) stated that

> Advocacy refers to the act of supporting or recommending a cause or course of action, undertaken on behalf of persons or issues. It relates to the need to improve systems and societal structures to create greater equity and better health for all. Nurses endeavour, individually and collectively, to advocate for and work toward eliminating social inequities” (p. 5, emphasis added)

This means that taken-for-granted ideologies, such as historical, political, and social processes, must be problematized or critiqued to develop a socially just set of competencies. Thus, reflexivity and advocacy are used to deepen understanding, and also to promote action toward health care practices that foster socially just health care (Clark et al., 2015).

Promoting justice and fairness and the public good has too often been narrowly constructed through a justice lens, without full integration of social justice, which helps nurses to respect diversity regardless of characteristics such as age, mental or physical (dis)ability, race, gender, gender identity, gender expression, and sexual orientation, in order to uphold the dignity of all. In addition, social justice must also include respect for diverse ways of knowing, doing, and being. There is a need to decolonize ethics to consider respect, reciprocity, and relationality (Wilson, 2008). When nurses use relational approaches to social justice they move beyond mere recognition of difference to understand the impact of social connections on political and social policies, including policies in health care. Further, principles of respect should include acknowledgement of the impact of the social determinants of health on Indigenous Peoples, and moreover, must also include respect for relational ways of being and knowing. Decolonizing nursing ethics requires that nurse leaders develop and use a moral compass that includes these principles of respect.

In order to use such a moral compass, nurses need to have moral courage. Moral courage has been described by Indigenous scholars
as a concept originally developed within psychology to mitigate the impacts of colonization amongst Indigenous youth (Brendtro et al., 2019). Moral courage and relational ways of being can be used to promote ethical competencies and virtues for nurses. Advanced practice nurse leaders must be aware of the impacts of colonization on nursing practice and have the courage to change their practice when needed.

In continuing to examine social justice, it is important to consider some of the current ethical challenges in public health—for example, providing nursing care during a pandemic. As we noted at the outset of this chapter, Kenny et al. (2010) challenged a dominant individualistic ethics framework and summarized relational concepts that inform our re-visioning of public health ethics. Public health practitioners address the health needs of communities and populations through actions that are taken at social and political levels, which means there is a need to address the social nature of nursing practice.3 Justice, as defined within the 2017 CNA Code of Ethics for Registered Nurses, is about the rights of others, distribution of resources, and promoting the common good. However, relational social justice involves fair access to social goods such as rights, opportunities, power, and self-respect: “This view of social justice directs us to explore the context in which certain political and social policies and structures are created and maintained” (Kenny et al., 2010, p. 10). Drawing on the work of Powers and Faden (2006), Kenny et al. suggested that social justice is “the foundational moral justification for public health” (p. 10). We believe this foundation can help advanced practice nurse leaders to consider how different social groups are affected by a collective practice that creates and shapes inequalities in health access and opportunity.

Relational theorists have long argued that people are relational beings who exist in a web, and that relationships and networks are structured socially and politically (Sherwin & Stockdale, 2017). Advanced practice nurse leaders ought to be critically reflexive about how relationships are structured by systemic patterns of privilege or disadvantage. They ought not to ignore the ways in which various social and political groups (such as those organized based on gender, race, class, ability status, age, ethnicity, and sexuality) influence moral practices across the profession.
Young (2011) describes social justice as a collective responsibility. In the context of advanced practice nursing, this means that advanced practice nurse leaders have a shared responsibility to critique and ameliorate the social practices that result in unjust actions. They have the knowledge, skills, and ability to transform many structural processes so that health care access and outcomes are morally good and socially just. It is imperative that advanced practice nurse leaders consider dignity, respect, and relational approaches when promoting social justice.

A key moral mandate for nurses in ensuring that health care access is equitable and accessible to all is the duty to provide care. This mandate comes from the obligations and responsibilities of nurses to their clients, and is enshrined in the 2017 CNA Code of Ethics for Registered Nurses. Given this moral mandate, the editors of this book recognized a need during the COVID-19 pandemic to provide additional resources to assist nurses to make decisions about their duty to provide care. In the next section, we describe a resource that was developed by Storch, Starzomski, and Rodney to provide support for nurses as they engage in ethical practice (see Appendix 1-1).

Duty to Provide Care During the COVID-19 Pandemic

Nurses have a moral obligation to support the best interests of the individuals, families, and communities for whom they provide care—an obligation that has been particularly challenging during the COVID-19 pandemic. In the spring of 2020, when the pandemic was beginning, the British Columbia (BC) government embarked on the development of comprehensive documents to guide nurses and other HCPs in caring for people with COVID-19. Although the guidelines were carefully crafted, the editors of this book found that the guidelines did not fully address the complex, profound challenges that registered nurses faced at the frontlines of care. Following a review of the BC provincial documents, as well as related provincial and territorial guidelines and national resources, we developed a resource designed to address the gaps that we noted. Our proposed resource was structured in four quadrants for ease of
application, and our goal was to promote equitable and effective health care approaches (see Appendix 1-1).

The four quadrants we proposed focused on the following:

1. What is the nurse’s duty to provide care?

2. How does a pandemic affect or alter the duty to provide care?

3. When is it acceptable for a nurse to withdraw from providing care, or refuse to provide care?

4. How should a nurse withdraw from providing care or refuse to provide care?24

Under quadrant one are items supporting the rationale for the duty to provide care, including the obligation of nurses to provide safe, competent, compassionate, and ethical care. This was founded on the ethical principle of beneficence—to benefit others. Nurses play an essential role in responding to a pandemic and in sustaining a functional and compassionate health care system.

Under quadrant two, where we outline how a pandemic affects and alters the duty to provide care, the reality of the risk of harm to nurses is highlighted, as well as the reality of a nurse’s relational obligations. Also shown are the expectations nurses ought to have of their leaders, such as regular consultations about addressing risks and harms.

In quadrant three, we address the circumstances where it would be justified to withdraw from the provision of care, or refuse to provide care. Nurses have two notable and, at times, conflicting obligations. There is the obligation to provide care, but there is also the obligation to determine the circumstances under which refusing to provide care would be justified if the nurse was being placed at an unacceptable level of risk, such as when there was a lack of personal protective equipment (PPE).

In quadrant four, we provide steps to follow when a nurse judges that they need to refuse to provide care, or withdraw from providing care. These steps include speaking to health care leaders about the need to withdraw from providing care as soon as possible, and in time for alternate arrangements to be made. Reasons should be given for the planned withdrawal of care, with a willingness to weigh and consider new information.
Ethical Decision Making for Advanced Practice Nurse Leaders

Given the earlier discussion about theoretical underpinnings for nursing ethics, in this section we provide opportunities for advanced practice nurse leaders to consider theoretical approaches to develop ethical decision-making skills as they engage in nursing practice. To facilitate this development, we include (a) a guideline for duty to provide care (see Appendix 1-1); (b) two ethical decision-making frameworks (see Appendices 1-2 and 1-3); and four case scenarios. These resources are intended to assist readers to apply ethical analyses, and suggest recommendations for action.

The four scenarios below are composites of real-life situations that the authors of this chapter have been involved in over the course of their careers in nursing ethics. A number of key topics are illustrated in the scenarios, including the following:

- advanced practice nurse leadership
- listening to and valuing diverse perspectives
- relational practice
- a critical social justice perspective
- the duty to provide care
- interprofessional collaboration, and
- duties and responsibilities of individuals, teams, and organizations.

We leave it to readers to consider and address the Reflective Questions we have provided after each scenario. We recommend that, if possible, these scenarios and questions be discussed in collaboration with colleagues in order to promote intraprofessional and interprofessional ethical dialogue.

We begin with the following Ethics in Practice scenario, where we describe the leadership challenges surrounding duty to provide care faced by a clinical nurse specialist during the COVID-19 pandemic.
Chapter 1: Nursing Ethics

ETHICS IN PRACTICE 1-1

Duty to Provide Care During the COVID-19 Pandemic

Marcie is a clinical nurse specialist, and also a new mother, who has just returned from maternity leave to her position at a long-term care facility. The facility is privately owned, and, prior to the COVID-19 pandemic, Marcie enjoyed her work with long-term care clients. She also appreciated the work of the diverse HCPs she worked with, including registered nurses, care aides, occupational therapists, physicians, and physiotherapists.

However, on her first workday back, Marcie realizes that the pandemic has been devastating for the facility, and that her staff colleagues are experiencing significant moral distress because of their difficulties meeting their clients' needs. Marcie becomes acutely aware of the shortage of PPE, and the effect that this deficit has had on her colleagues, who are often working short-staffed. The stories being told to her about the many residents who died alone are sad in themselves, but learning about the lack of staff to even hold a dying person's hand is heartbreaking. When she proceeds to follow up on the reasons for the facility being short-staffed, she finds that an absence of effective staffing guidelines, fear, and a lack of PPE seem to be key causal factors.

Marcie raises her concerns with the nurse manager in the facility, urging him to assess the situation and develop solutions for better and safer care, both now and in the future. The manager considers Marcie's request and asks her for help, as he has been overwhelmed with all the issues facing the facility as a result of the pandemic.

Although Marcie knows that being a nurse comes with a duty to provide care, she believes that more guidance is needed about the limits of that duty, and that senior managers and health authorities have a corresponding duty to secure adequate health care funding. Fortunately, Marcie remembers accessing guidelines developed during the COVID-19 pandemic which address four applicable matters: (1) nurses' duty to provide care; (2) how that duty might be altered by negative circumstances; (3) when it would be acceptable to refuse to provide care; and (4) how a nurse might refuse to provide care or withdraw from care.

Marcie subsequently reflects on how she and other HCPs could work together, and with senior leaders in the care facility, to influence positive change. Marcie has already taken on significant leadership in considering the staff's concerns but is struggling to determine her next steps.

REFLECTIVE QUESTIONS

1. How might Marcie collaborate with colleagues to develop a plan to approach management regarding their concerns?
In the following Ethics in Practice scenario, we explore the ethically challenging context of treatment withdrawal when the patient no longer wants to proceed with treatment, but the healthcare team and the patient’s family believe that there may still be hope for life.

**ETHICS IN PRACTICE 1-2**

*Treatment Options in a Complex Critical Care Case*

Abdul, a 56-year-old man who immigrated with his family to Canada five months ago, was admitted to Mercy Hospital, a large quaternary care teaching hospital, after suffering a major myocardial infarction (MI) at his home. Abdul’s adult son, Imran, was with him at the time, and called an ambulance. Although Abdul promptly received oxygen and cardiac medications from the paramedics who arrived at his home, and was admitted to an acute care hospital within an hour of his MI, the damage to his heart was such that he required immediate critical care interventions, including mechanical ventilation, to survive.

Because of the extensive blockages in his coronary arteries, Abdul has been booked for emergency open heart cardiac surgery later that day to attempt to revascularize his heart. He is unable to consent to the surgery, as he is unconscious. However, it appears that Abdul would not want the cardiac surgery. When the cardiac surgeon arrives to assess Abdul, Imran tells the cardiac surgeon that his father told him, while he was having his heart attack, that he did not want to be saved if he would not be able to “come back as himself,” and that he did not want to be a burden to his family.

If Abdul does recover, he will be facing an extensive program of cardiac and neurological rehabilitation. Because he is intubated for ventilation, and unconscious, Abdul is unable to communicate with the surgeon. Imran is named as Abdul’s
substitute decision-maker, and has told the surgeon what his father said during his MI. The health care team, including the clinical nurse specialist, Melissa Tang, realizes that the ethics of Abdul’s situation are complex, and she calls Ethics Services to request an ethics consultation.

While Melissa and the health care team are waiting for the ethics consultant to come to the unit, Abdul’s wife, Salma, and oldest daughter, Nassim, arrive at his bedside. Open heart surgery is a procedure that Abdul and his family are not familiar with, and his family is frightened, particularly because they cannot communicate with him. When the family hears about the potential complications of the surgery and the extent of the post-operative recovery that Abdul would have to undergo, they are concerned. English is not their first language, and as they listen to what they are being told, they have little time to process what they are hearing. They are frightened, bewildered, and grieving.

Yasmin Farahani, a nurse ethicist, arrives in Abdul’s room about 30 minutes after his family members. She has been informed about escalating staff concerns regarding how best to support Abdul and his family during the crisis they are experiencing. Yasmin asks Abdul’s family for permission to spend some time with them to listen to their questions and concerns, and also offers to find an interpreter to assist with their conversation. She explains that she is the hospital’s ethics consultant, and is available to explore and respect Abdul’s previously stated wishes, consider his best interests, listen to and respond to his family’s concerns, and to support hospital staff in caring for him.

Given the complexity of Abdul’s situation, and the concerns of his family and the staff, the use of an ethical decision-making framework can provide guidance to explore the questions below.

**REFLECTIVE QUESTIONS**

1. What steps could Yasmin take to set up an effective team meeting for Abdul’s family?

2. Why is Yasmin’s offer of an interpreter important in this situation?

3. How can the team ensure that Abdul’s spiritual beliefs and ethnocultural values are being considered as they develop a plan of care?

4. How can Yasmin and Melissa support the health care team and Abdul’s family as they engage in an ethical decision-making process that is focused on Abdul’s prior wishes and his best interests?

5. How can Melissa, as an advanced practice nurse leader, foster dialogue among the ethics consultant, HCPs in the critical care area, and Abdul’s family members?

6. How could Melissa and the team best prepare Abdul’s family for the uncertainty of his prognosis, including his potential death?
In the next Ethics in Practice scenario, we address a complex home care situation in an isolated Indigenous community. The community has limited available health care resources, presenting significant challenges to the patient, her daughter, HCPs, and the overall community.

**ETHICS IN PRACTICE 1-3**

**A Home Care Challenge in an Indigenous Community**

Sarah is a widowed 68-year-old Indigenous woman who has had mild dementia for the past four years. She lives in a small home with her 46-year-old daughter, in a rural community of Indigenous people in northern Alberta. The community members support one another, and access the nursing station for their health care needs when required.

Sarah and her daughter, Daanis, have few transportation options and limited access to regional health care resources in Alberta or nearby Saskatchewan. The nursing station in their community is staffed by four nurse practitioners who provide regular access to primary health care in the community, but there are no specialized long-term care resources. One of the nurse practitioners, James, sees Sarah regularly in the nursing station clinic. Sarah has told her daughter that she trusts James and hopes that he can continue to look after her.

Sarah has limited financial resources. Further, she is at the stage where, in order to remain at home, she needs more home care than can be provided by her family, the nurse practitioners, or other community members. However, Sarah has consistently expressed that her preference is to remain “on her land,” close to her daughter, rather than being sent to a long-term care facility outside of her community where the people and the land will be strange to her.

**REFLECTIVE QUESTIONS**

1. As an advanced practice nurse leader in Sarah’s community, how might James be able to support her autonomy and her well-being?

2. What key information does James need about Sarah and her family situation to help him identify key priorities in her care?

3. Why it is important for James to build collaborative and trust-based relationships with Sarah and other Indigenous people in the community?

4. How can James promote the development of trust between HCPs outside of Sarah’s community and Sarah and her family?
In the last scenario of this chapter, we present an ethically complex case of a refugee who requires end stage renal failure treatment immediately upon arrival in Canada. As the health care team strives for a positive patient outcome, resource allocation questions are raised and different layers of government policies and guidelines are considered.

**ETHICS IN PRACTICE 1-4**

**Care for a Refugee Claimant with Kidney Failure**

Fatima is 27-year-old lesbian who uses she/her pronouns. She left Iran after being persecuted because of her sexual orientation, and has been living in a refugee camp in Africa for the past two years. This year, a church in BC sponsored Fatima to come to Canada. After all her struggles, she is overjoyed with the prospect of living a better life in BC. However, on her trip to Canada, Fatima collapses in her seat as the plane is landing and is immediately taken to an emergency department (ER) near the airport. In the ER, it is determined that Fatima is in end-stage kidney failure and needs immediate dialysis. With the help of an interpreter, Fatima consents to begin dialysis and is transferred to a hospital with hemodialysis capacity.

After several months of hemodialysis, Fatima’s condition improves somewhat; however, she is unable to seek work because of her dialysis schedule and overwhelming fatigue. She now worries about whether she will be able to remain in Canada, as the church is only sponsoring her for one year, until she is able to get herself established.

Colette, a nurse practitioner in the nephrology/transplant program, has organized a team meeting, with Fatima in attendance, to discuss a long-term plan of care. In the meeting, Fatima says that her sister, who still lives in Iran, has volunteered to donate a kidney. The program manager expresses concern about this. He states that having Fatima’s sister assessed as a potential kidney donor in Iran, and then having her come to Canada for the donation if she is suitable, is fraught with complexity because of all the red tape and uncertainty about who would pay for all the costs that need to be incurred. In the meantime, until Fatima’s refugee claim has been sorted out, she will need to remain on dialysis, and will not be placed on the deceased donor transplant waiting list.

Fatima is stressed and feeling despondent about her future. She asks to speak with Colette after the meeting. Fatima states that her dream of living safely and peacefully in Canada looks out of reach, and that she does not see a future for herself. She tearfully asks for Colette’s help.
Conclusion

The development and use of ethical theory in nursing has a rich history which continues to evolve. As we have described in this chapter, this evolution requires nurses to focus on a number of areas, including relational practice and social justice. A broad notion of social justice is necessary for nurses to enact their responsibilities and obligations to address the ethical issues they face in their practice, as well as to be part of resolving complex societal ethical concerns. In order for nurses to do so, effective ethical decision making grounded in nursing ethics is key. The case scenarios in this chapter provide an opportunity for nurses, advanced practice nurse leaders, and other HCPs to use ethical theory and decision-making frameworks to resolve ethical challenges.

As authors of this chapter, we believe that a focus on a socially connected model of moral agency has had, and will continue to have, significant benefits for nurses in practice, especially advanced practice nurse leaders. As our lead-in quote for this chapter indicates, and through our shared research and study over many years, we have come to understand the value of advanced practice nurse leaders as moral compasses within practice settings. We continue to be interested in learning more about how to promote quality practice environments for safe, competent, and ethical practice. Fostering proactive communication and trust within and among HCP groups,

REFLECTIVE QUESTIONS

1. How should Colette respond to Fatima’s request? What is Colette’s role in helping Fatima plan for her future in Canada?

2. What values should be considered in planning for Fatima’s care?

3. What aspects of social justice should be taken into account in Fatima’s case?

4. Who should Colette involve in future discussions about Fatima’s care?

5. What resources might Colette use to help her to provide the care that Fatima requires?
and across all levels of health care organizational hierarchies, is foundational to supporting all practicing nurses.

What this means to us now is that all of us in nursing—student nurses, nurse educators, nurses in practice, advanced practice nurses, and nurses in formal health care leadership roles—whether in practice, education, research, or health care planning and delivery—should see ourselves as moral agents charged with the collaborative leadership responsibility of guiding ourselves and others. As we move toward understanding what is happening, what ought to happen, and how to navigate the difference, we need to cultivate wisdom, courage, and humility. We believe that cultivating these three qualities will help all of us, as nurses, to provide and promote ethical nursing practice now and in the future.

**QUESTIONS FOR REFLECTION**

1. **In considering your own values and beliefs, how do you think they influence your approach to ethical concerns/issues/dilemmas? What are the implications for you as a moral agent?**

2. **How might you initiate discussions about ethics among health team members?**

3. **What actions can you take to foster a social justice perspective in your health care setting?**

4. **What actions can individual advanced practice nurse leaders take to strengthen their autonomy as moral agents? As members of organizations? In professional groups?**

5. **How might advanced practice nurse leaders work with HCPs, governments, and other organizations to decrease moral distress and foster moral resilience in health care settings?**

6. **How can relational values be fostered in health care organizations so that nurses and other HCPs are better supported in enacting a relational ethic?**

7. **What are some key initiatives that nurse educators could promote to foster ethical practice across diverse groups of health care providers?**

8. **How can advanced practice nurse leaders model ethical practice within and across diverse health care groups?**
Endnotes


2 Its office was previously located at the University of Surrey, but moved to the University of Exeter with Ann Gallagher as Editor-in-Chief. Many Canadian nurses have served on the editorial board; many more have published within the journal.

3 For further discussion about public health ethics, see Chapter 4.

4 For more information about the duty to provide care and conscientious objection, please see the British Columbia College of Nurses & Midwives (n.d.) Duty to Provide Care and the CNA (2017) Code of Ethics for Registered Nurses.

References


APPENDIX 1-1

The Ethical Duty of Nurses to Provide Care During a Pandemic*

Janet L. Storch, Rosalie Starzomski, and Patricia Rodney
1. What is the nurse’s duty to provide care?

The duty to provide care is foundational to nursing practice. The duty to provide care is the obligation of nurses to provide safe, competent, compassionate, and ethical care. This duty arises from the ethical principle of beneficence, which means to benefit others. Nurses play an essential role in responding to a pandemic and in sustaining a functional and compassionate health care system.

3. When is it acceptable for a nurse to withdraw from providing care, or refuse to provide care?

Each nurse must first weigh the evidence about the risks involved in providing care, or continuing to provide care. Each nurse must justify whether the expectations placed on them is unreasonable, taking into account the tasks they are being asked to do, mitigation strategies (such as appropriate personal protective equipment) that is provided, and their personal circumstances. Nurses can withdraw from providing care, or refuse to provide care, if they believe that providing care would place them and/or others at an unacceptable level of risk, such as when there is a lack of personal protective equipment (gowns, masks, gloves). Please refer to Endnote #4 in this chapter for more information about reasons for a nurse withdrawing from providing care.

4. How should a nurse withdraw from providing care or refuse to provide care?

The nurse should speak to their leader about their need to refuse to provide care or withdraw from care. The nurse’s decision should be made known, as soon as possible, in time for alternate arrangements to be made. Risks to the person(s) in care must be considered. Reasons should be given for the planned withdrawal of care, with a willingness to discuss and consider improved personal protective equipment and/or a different assignment, if possible. The nurse must then weigh and consider any new information received from the leader to determine if their decision to refuse to provide care, or withdraw from providing care, would change.

2. How does a pandemic affect or alter the duty to provide care?

The risk of harm to a nurse can be serious or potentially life-threatening. Nurses must consider their risks and take all measures to avoid serious harms. Nurses must also consider their personal relational obligations, such as parenting duties and other caregiving commitments. Nurses should expect their leaders to engage in regular consultations with them to prevent and address harms in practice areas and to consider risks to persons in their care. Proactive and regular debriefing and support services ought to be provided for nurses and health care leaders to sustain their ability to provide care.

* Please also refer to your own organization’s guidelines about duty to provide care, as well as provincial/territorial nursing standards of care.
APPENDIX 1-2

Storch Model for Ethical Decision Making: Guiding Questions for Clinical Decision Making

Janet L. Storch
1. INFORMATION AND IDENTIFICATION

- Talk with all parties involved. From that conversation, there should emerge a central story.
- Learn about the patient’s medical status and the expectations they or their family have for outcomes, as well as the expectations of the health care team.
- Gather non-medical information about social conditions, family roles and relationships, quality of life, and power dynamics in the situation.
- Determine level of competency/capacity.

2. CLARIFICATION AND EVALUATION

Consider the values involved:

- What is the significance of the values involved—oral, religious, cultural, personal, professional?
- What is the significance of these values to the people involved?
- What is the story behind the value conflicts?
- Consider the ethical principles involved:
  - Which principles might be most important in this situation?
  - Are some principles in conflict with others?

Consider the social expectations and the legal requirements involved:

- Is there any institutional history on a similar situation?
- What institutional policy requirements are important?
- What legal provisions need to be considered?

Determine a range of potential actions and their consequences:

- Focus on ethically acceptable courses of action.
- Build consensus around which action is most fitting for the situation.
• Ensure patient, family, and team have common understandings about the plan of action.
• Plan to meet again to consider consequences/learning.

3. ACTION AND REVIEW

FIGURE 1-2-1

Storch Model for Ethical Decision Making

- Beneficence
- Non-Maleficence
- Autonomy
- Justice
- Veracity
- Fidelity

Social Expectations
Legal Requirements

Range of Actions/
Anticipated Consequences

Action & Review

One's Values/Beliefs
Values/Conflicts

Values/Conflicts of Others

Professional Code of Ethics

Ethical Principles

Appendix 1-2
APPENDIX 1-3

An Ethical Decision-Making Framework for Individuals

Michael McDonald (adapted by Rosalie Starzomski and Patricia Rodney)
1. COLLECT INFORMATION AND IDENTIFY THE PROBLEM(S)

a. Identify what you know and what you do not know, but need to know. Be prepared to add/update your information throughout the decision-making process.

b. Gather as much information as possible on the patient’s physical, psychological, social, cultural, and spiritual status, including changes over time. Seek input from the patient, as well as the patient’s family, friends, and other health care team members.

c. Investigate the patient’s assessment of their own quality of life and their wishes about the treatment/care decision(s) at hand. This includes determining the patient’s decision-making capacity, as well as determining which family member(s) the patient wants involved in discussions and decision making about their treatment/care. If the patient does not have decision-making capacity, look for an advance directive. Identify a substitute decision maker for a patient who does not have decision-making capacity and seek evidence of the patient’s prior expressed wishes. Regardless of the patient’s decision-making capacity, involve the patient as much as possible in all decisions affecting them.

d. Include a family assessment: What are the various roles, relationships, and relevant “stories”?

e. Consider implications for social justice. Identify areas where patient and family resources for health and health care may be compromised.

f. Identify the health care team members involved, and circumstances affecting them.
g. Summarize the situation briefly, but with all the relevant facts and circumstances. Try to get a sense of the patient’s overall health and illness trajectory. Determine what is most important to the patient at this stage of their illness and what their wishes are for the future.

h. What decisions have to be made? By whom?

2. **SPECIFY FEASIBLE ALTERNATIVES FOR TREATMENT AND CARE**

a. Use your clinical expertise to identify a wide range and scope of alternatives. Avoid binary thinking (such as treat/do not treat) and lay out carefully tailored alternatives for the problems you have identified.

b. Identify how various alternatives might be implemented (for example, limited time trials of treatments).

3. **USE YOUR ETHICS RESOURCES TO EVALUATE ALTERNATIVES**

**Principles/Concepts**

*Autonomy*: What does the patient want? How well has the patient been informed and/or supported? What explicit or implicit promises have been made to the patient?

*Nonmaleficence*: Will this harm the patient? Others?

*Beneficence*: Will this benefit the patient? Others?

*Justice*: Consider the interests of all those (including the patient) who have to be taken into account. Are biases about the patient or family affecting your decision making? Treat like situations alike.
**Fidelity:** Are you fostering trust in patient/family/team relationships?

**Care:** Will the patient and family be supported as they deal with loss, grief, and/or uncertainty? What about any moral distress of team members? What principles of palliative care can be incorporated into the alternatives?

**Relational Autonomy:** What relationships and social structures are affecting the various individuals involved in the situation? How can these relationships and social structures be used?

**Standards**

Examine professional norms, standards and codes, legal precedents, health care agency policy.

**Personal judgments and experiences**

Consider your personal judgments and experiences, and those of your colleagues, as well as other members of the health care team.

**Organized procedures for ethical consultation**

Draw on the expertise of other health care providers as needed, and use the ethics resources available in the health care agency. Consider formal case conferences, an ethics committee meeting, and/or inviting an ethics consultant to provide assistance, especially if the situation is complex and/or conflicted.

4. **PROPOSE AND TEST POSSIBLE RESOLUTIONS**

   a. Select the best alternative(s), all things considered.
b. Perform a sensitivity analysis. Consider your choice(s) critically: Which factors would have to change to get you to alter your decision(s)? Further, carefully consider whether you want to maintain or change your previous choice(s).

c. Think about the effects of your choice(s) upon the choices of others. Are you making it easier for others (health care providers, patients and their families, etc.) to act ethically?

d. Is this what a compassionate health care provider would do in a caring environment?

e. Formulate your choice(s) as a general maxim for all similar situations. Think of situations where it does not apply. Consider situations where it does apply.

f. Are you and the other decision makers still comfortable with your choice(s)? *If you do not have consensus, revisit the process.* Remember that you are not aiming at the perfect choice, but the best possible choice. If no consensus is forthcoming, is it possible to reach a compromise?

g. Ensure that there is a clear implementation plan. Ensure that the rationale and details of the plan are clearly communicated to all those who will be affected (patient, family, and health care providers). Be sure that the implementation plan includes feedback from relevant individuals (the patient, family and friends, health care providers).

5. **MAKE YOUR CHOICE**

Live with your choice and learn from it! Seek feedback on the process from all those involved. Take the opportunity to reflect on how you will deal with other challenging situations in the future. Consider organizing follow-up debriefings, continuing education sessions, and, if needed, make changes to related policies and procedures.
IT MAY BE SURPRISING TO SOME that the central ethical principles accepted in health care practice and health care research were developed in response to reports of “research” ethics abuses. As these research abuses came to light, physicians and philosophers in the United States issued the *Belmont Report* in 1978, which was then published in the Federal Register in 1979. The report identified three basic principles for research with people: respect for persons,
beneficence, and justice. These principles were enhanced, used in codes of ethics and other documents, and practiced in evaluating procedures in clinical settings and research environments. They continue to be key to ethical research today.

In this chapter, we will first discuss some of the major research ethics abuses in Europe, the United States and Canada. We pay special attention to those abuses that involved compliant nurses and also played a prominent role in subsequent measures adopted to eliminate or reduce harms in the name of research. We then turn to the development of codes of ethics and processes (in particular Research Ethics Boards, called REBs). We focus on Canadian provisions for guidance, including the development of the Tri-Agency funding body, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2) guidelines for research, and an explanation of how REBs function. Throughout, the place of nurses in these developments will be examined.

In the latter part of this chapter we use Ethics in Practice case studies to explore the four main roles that advanced practice nurses have related to research ethics: in practice; as managers and leaders; as researchers and research coordinators; and as REB members. We close the chapter by offering areas for research ethics on the moral horizon and reminding nurses why vigilance and leadership must be ongoing when it comes to research ethics.

**The Mid-Twentieth Century: A Dubious Era in Medical Research**

We begin with a discussion of historical studies that sounded the alarm regarding scientists and health care practitioners who failed to honour the intrinsic value of human beings and respect for human dignity (Canadian Institutes of Health Research et al., 2022). Ours is not an exhaustive review of known atrocities, and certainly others remain untold.
Serious Research Abuses During World War II and in the United States

When the world became aware of the serious human rights abuses inflicted during World War II—including human experimentation—people were shaken. Two of the principal partners in the Axis alliance, Nazi Germany and Imperial Japan, conducted involuntary, inhumane experiments on prisoners of war and so-called “undesirables” and “enemies of the state” for reasons that included determining potential outcomes for their military (Emanuel et al., 2008; Harvard Law School Library, 2020; Tsuchiya, 2008; Weindling, 2008). For example, in one German experiment, researchers sought to determine how long a war pilot might live when shot down over the English Channel, based upon how long prisoners could survive in icy cold water. These trials eventually became known as the infamous “cold experiments in Dachau.” Dr. Josef Mengele and Dr. Sigmund Rascher were the German physicians viewed as responsible for this horrific research (Seidelman, 1988). Investigators in similar projects studied the effect of exposing prisoners to exotic diseases and phosgene gas, a biological warfare agent, to determine how humans might respond, and then to develop remedies to protect future soldiers (Luna & Macklin, 2009). Scholars like Copeland (2021) and Shields and Benedict (2014)—and victims like Eva Mozes Kor (Mozes Kor & Wright, 1995), one of “Dr. Mengele's Twins”—describe the roles that nurses and midwives willingly (and unwillingly) played in the Nazi medical experiments.

Despite the powerful condemnation of Nazi medicine and medical research at the Nuremberg trials (1946–47), experimentation on humans persisted and even increased after World War II in Western industrialized nations (Beecher, 1966; Mosby, 2013). Researchers typically enrolled healthy people from populations made vulnerable by their circumstances. Such circumstances included people from government institutions such as prisons, military camps, and homes for people with disabilities. In addition, investigators used medical students and family members (Lederer, 1995). Other experiments in the United States that caught the attention of the world include
the initial launch and subsequent continuation of the Tuskegee Syphilis Study (1932–1972),
2. the Willowbrook State School hepatitis studies (1950–1970),
3. the Salk polio vaccine testing at Polk State School and Watson’s Crippled Children’s Home (1950s), and
4. the harvesting and use of Henrietta Lacks’s unique “HeLa” cells (1951 to present).

Nurses had a role in all of these experiments. These nurses may have been somewhat aware that research activities were being conducted without the subjects’ full knowledge. For example, in 1932, the United States Public Health Service launched a study designed to determine the natural history of untreated syphilis in Black populations. Initially titled the “Tuskegee Study of Untreated Syphilis in the Negro Male,” what is now commonly referred to as the Tuskegee Syphilis Study began when there was no known treatment for syphilis. Researchers and support staff recruited 600 Black men from a poor community in Alabama (Dunn & Chadwick, 2004; Jones, 2008). The study was technically well designed, with a treatment group of men who had syphilis and a control group of men who did not have the disease. A local Black nurse named Eunice Rivers, who had trained at the Tuskegee Institute’s School of Nursing, was hired to be the on-site representative (Dunn & Chadwick, 2004). The start of study predated the discovery of penicillin; thus, since at the time there was no known treatment for syphilis, the men were all given only check-ups and aspirin by physicians and public health nurses. But when penicillin was discovered as a cure for syphilis in 1942, most subjects were actively denied penicillin, and the devastating effects of untreated syphilis continued to be observed. The study was only stopped in 1972 after an article in the New York Times (Heller, 1972) prompted widespread public outrage.

Nurses also took part in the Willowbrook State School experiment, conducted in New York between 1950 and 1970, which studied the effects of the hepatitis virus on children with developmental disabilities. After 1964, researchers deliberately infected children with hepatitis as a requirement of admission to the institution (Robinson & Unruh, 2008). Similarly, in the 1950s, Jonas Salk used children from the Polk State School and the Watson
Home for Crippled Children (in addition to himself and his family) as research subjects to study the effects of his polio vaccine (Juskewitch et al., 2010; Meldrum, 2008). Nurses participated in these studies too, or at least would have been involved in caring for the children and witnessing the effects of the trials.

Finally, we briefly outline the case of a Black woman named Henrietta Lacks, who became unwittingly famous for her rare and immortal “HeLa” cell line. In 1951, at 31 years of age, Lacks was diagnosed with aggressive cervical cancer which required regular gynecological check-ups (Skloot, 2010). Unbeknownst to Lacks, the visits were not just for her clinical care; they were also for research. The nurses involved in Lacks’s visits would have known that the “check-ups” she was required to attend were, in fact, to regularly obtain cells from her cervix, named after her as “HeLa” cells. Consent for the research purposes was not obtained, as was the norm at the time. “HeLa” cells have become a billion-dollar industry and are still widely used to study the effects of toxins, drugs, hormones, viruses, and gene mapping. Yet for many years, Lacks remained virtually unknown, and her family was impoverished; they could not afford health insurance (Skloot, 2010). In 2021, the estate of Henrietta Lacks sued a biotechnology company, accusing the company of continuing to profit from cells that physicians at Johns Hopkins Hospital took in 1951 without Lacks’s knowledge or consent (Associated Press, 2021).

**Selected Serious Research Abuses in Canada**

Canada’s history also includes ethically dubious medical research during the mid-twentieth century. Particularly egregious instances include

- nutritional studies in Indigenous communities and residential schools (1942–1952),
- lysergic acid diethylamide (LSD) studies at Allan Memorial Institute and Kingston Prison for Women (1950s),
- anaesthetic testing on a university student at the University of Saskatchewan (1961), and
- genetic testing on blood samples from members of the Nuu-chah-nulth First Nation (1982–2008).
Between 1942 and 1952, some of Canada’s leading nutrition experts conducted nutritional studies in Indigenous communities and in the residential school system. In 2013, historian Ian Mosby exposed that one of the most ambitious studies, performed by Canada’s Department of Indian Affairs, was conducted as the “James Bay Survey of the Attawapiskat and Rupert’s House Cree First Nations.” In these studies, researchers denied control and treatment groups of already malnourished children adequate nutrition. Nurses were instrumental in implementing the study procedures. To control as many factors as possible, these procedures continued, even though they were known to harm the children. For example, even previously available dental care was denied in some settings because the researchers wanted to observe the state of dental caries and gingivitis with malnutrition. Parents were not informed, nor were consents obtained. Even after children died, the experiments continued. MacDonald et al. (2014) titled their paper on the topic “Canada’s shameful history of nutrition research.” An interviewer from the Canadian Broadcasting Corporation’s (CBC) Unreserved program spoke to Ian Mosby in April 2021 in the episode “The dark history of Canada’s Food Guide: How experiments on Indigenous children shaped nutrition policy” (Tennant, 2021).

During the 1950s to the 1960s, experiments investigating the psychedelic drug LSD as a potential cure for mental illness were conducted in various locations across Canada. The most famous of these, Project MKULTRA, was led by Dr. Ewen Cameron, a prominent psychiatrist affiliated with the Allan Memorial Institute in Montreal, who had been called upon to assess the fitness of Nazi war criminals to stand trial at Nuremberg (Collins, 1997; Lemov, 2011). Cameron began to employ harmful techniques on his patients without their realization that they were being experimented on. The procedures included shock therapy, supplemented by large doses of LSD, and putting patients into insulin or drug-induced comas for weeks, during which they were subjected to taped messages for 16 hours per day. Cameron’s patients suffered significant, ongoing harm as a result of these procedures. Some of these former patients successfully sued the United States Central Intelligence Agency, while other patients sued the Canadian government; both were funders of Cameron’s projects. The CBC program
The Fifth Estate followed this story for many years (Cashore & Smart, 2017).

At the Kingston Prison for Women in the early 1960s, 23 inmates were involuntary research subjects in a study of the psychotherapeutic use of LSD. This practice was reported to Correctional Services Canada in 1965; the report, however, led to further investigations on the use of LSD and shock therapy (Gilmore et al., 1998).

In 1961, Walter Halushka, a 21-year-old student at the University of Saskatchewan, agreed to be a subject to test a new anaesthetic called Fluoromar at the University Hospital. Halushka was told that the test would last a couple of hours and that it was “perfectly safe.” In fact, the researchers had never administered the anesthetic before. Halushka and one witness signed a form titled “Consent for Tests on Volunteers” (Veatch, 1977). Normally, operating room nurses would review the consent form with a patient; there was no specific mention of such a process in the court testimony. The form Halushka signed was inadequate, given that the standard in 1961 required that research subjects understand the procedure and its risks. Unfortunately, none of the nurses questioned the two doctors or requested more information about the procedure (at the time, nurses questioning doctors was not the practice). Halushka appeared for the test, the anaesthetic was administered, and shortly thereafter he suffered a cardiac arrest. He was resuscitated, but remained unconscious for four days. Halushka was discharged from the hospital after 10 days, having been paid $50 for the test. The procedure inflicted brain damage that prevented him from continuing his university studies.

In the landmark case of Halushka v. University of Saskatchewan (1965), Walter Halushka sued the hospital and the two physicians and was awarded $22,500. Justice Hall ruled that

the consent given by a patient to a physician or surgeon, to be effective, must be an ‘informed’ consent freely given…. The subject of medical experimentation is entitled to a full and frank disclosure of all the facts, probabilities and opinions which a reasonable man might be expected to consider before giving his consent.

(Veatch, 1977, pp. 291–293)
The examples of research ethics abuse described thus far are commonly cited as having established the standard for consent to research today.

Another well-known breach of research ethics in Canada occurred from 1982–1995. During those years, Nuu-chah-nulth First Nation provided a UBC researcher with blood samples for genetic testing to study the high incidence of rheumatic disease, an area of concern in their community. The study team included physicians and medical students as well as nurses. Years later, the community learned that the researcher had relocated to universities in two different countries and had taken the specimens with him. In fact, the researcher had gone on to conduct diverse research that was not part of the original consent, including biological anthropology research that the Indigenous community perceived as particularly harmful. In response, the Nuu-chah-nulth Tribal Council Research Ethics Committee (2008) developed research protocols that were responsive to the context of their unique communities. The remaining blood samples were eventually returned to British Columbia in 2004, and destroyed in 2008 (Arbour & Cook, 2006; Ha-Shilth-Sa, 2013; Wiwchar, 2004).

ETHICS IN REFLECTION 2-1

Acknowledging Past Wrongs

In most of the experiments described above, nurses would have been involved in the care of the patients. Nurses either accepted or ignored serious ethical dilemmas. We wonder why (particularly when children and adults who were already marginalized and in vulnerable circumstances were involved) nurses did not intervene or even report the wrongful practices underway. For example, I (Janet) lived in Montreal during part of the period that the LSD experiments were being conducted. A nurse colleague who worked at Allan Memorial witnessed and told me about Cameron’s irregular practices, which seemed, to her, to be harmful. My colleague felt helpless and unable to even report the wrongs.

Looking back to this period, we must remember that the voices of nurses were rarely welcomed and nurses could be disciplined for daring to speak up or to even question a practice. We acknowledge that social, political, economic, and professional pressures have always existed and will continue to exist; these factors impact how nurses provide care (Copeland, 2021) and emphasize the importance of nursing leader-
Responses to Research Ethics Abuses

In response to ongoing revelations about ethics abuses in the name of research, in this section we review the key ways in which the Euro-Western world responded with codes of ethics, REBs, and ethics organizations. These structures were designed to meet three ethical objectives: promoting socially beneficial research, respecting the dignity and rights of research participants, and maintaining trust between the research community and society as a whole (McDonald, 2000).

Codes of Ethics

Before the 1950s, researchers engaged in human experimentation relied on informal guidelines or professional codes of ethics (Halpern, 2004). These ethical guidelines and codes were rooted in a worldview that reflected (and continues to reflect) the dominant traditions of Euro-Western moral philosophy, cultural and methodological perspectives, and political and social theory (Hayward et al., 2021, p. 403). Early work on such codes included the Berlin Code, prepared in 1900. The initial response by medical observers to World War II research abuses, particularly the Nazi Medical Experiments, was to establish some rules for research through the use of codes of ethics. The Nuremberg “Doctors’ Trial” in 1946–1947, the subsequent Nuremberg Code (1949), and the World Medical Association’s Declaration of Helsinki (1964) laid the fundamentals of biomedical ethics with regulations and requirements for ethical procedures. Thus, ethical standards of informed consent have been in place since World War II. Medical practitioners and researchers have used these codes as important guides for practice and research, yet as noted, at times they have been ignored.
The most influential of these documents was the *Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). The *Belmont Report*, seen as the cornerstone of modern health care ethics (including research), outlines a set of core ethical principles: respect for persons, beneficence, and justice. The principles were promoted in the release of the 1979 text titled *Principles of Biomedical Ethics*, by Tom L. Beauchamp and James F. Childress (2019). The wide use of these three to four principles (the Beauchamp and Childress text includes a fourth principle, nonmaleficence) advanced the moral theory that has become known as *principlism*.

**Research Ethics Boards**

Starting in the 1960s, government agencies in industrialized nations took on a greater role in funding medical research. A review process was set up as the main mechanism to provide ethical oversight of research involving humans in accordance with established standards and requirements. Referred to in Canada as Research Ethics Boards (REBs) (and elsewhere as Institutional Review Boards [IRBs], Research Ethics Committees [RECs], etc.), the main responsibility of REBs is to protect the rights and welfare of human research participants by ensuring that studies are conducted in a safe, ethical, and socially responsible way.

Typically, REBs are established by institutions such as universities, hospitals, and other health care facilities to review and approve applications related to research involving human participants. REBs have the power to propose changes, to refuse, and to stop experiments that fall short of ethical requirements. A secondary role for institutional REBs is to protect the interests of the institution and researchers (Stark, 2011). Independent REBs provide ethical review for researchers conducting research projects outside the auspices of an institution. The REB structure is a crucial mechanism to ensure research participant safety and successful research that benefits patients and their families, health care providers, and communities.
Ethics Organizations

Developments in research ethics during the 1960s and 1970s also prompted the founding of a number of ethics centres, including The Hastings Center near New York in 1969, The Kennedy Institute of Ethics at Georgetown University in Washington DC in 1971, and other centres in the US. In Canada, ethics centres and groupings formed in Montreal, Toronto, Halifax, Winnipeg, Edmonton, and Vancouver.

Research Ethics Structures and Guidance in Canada

In this section, we summarize Canada’s unique system of research ethics. This includes the Tri-Agency research funding infrastructure: Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC). In addition, we review the Interagency Advisory Panel on Research Ethics; the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Canada’s standard for ethical research; and the structure of REBs.

The Tri-Agency Funding Infrastructure

An ideal system of research ethics takes a holistic “lifecycle approach” that acknowledges the range of ethical issues that exist, or may develop, throughout the complete cycle of scientific knowledge—from creation to translation (Anderson et al., 2011). Over time, the Government of Canada streamlined the research funding process by creating three federal granting councils: CIHR, NSERC, and SSHRC. Collectively, these councils are referred to as the Tri-Agency. They are the major sources of research funding for Canadian post-secondary institutions:

- **CIHR** funds research primarily intended to improve or have an impact on health, produce more effective health services and products, and strengthen the Canadian health care system (founded in 2000);
• NSERC funds research primarily intended to advance knowledge in the natural sciences and engineering (founded in 1978); and

• SSHRC funds research intended to add to our understanding and knowledge of individuals, groups and societies (founded in 1977).

Nurses mainly apply for funding through CIHR or SSHRC.

To address the need for common research endeavors, in 2001 the Government of Canada also created the Interagency Advisory Panel on Research Ethics (PRE or the Panel) (Panel on Research Ethics, 2023a). This Panel was specifically developed to manage the ethics policy of the funding agencies and to steward the evolution and interpretation of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS), the joint research ethics policy statement of CIHR, NSERC, and SSHRC, first published in 1988. Institutions eligible to administer and receive Tri-Agency research funding must agree to adhere to the TCPS as a condition of funding.

**Canada’s Standard for Ethical Research:**
**Tri-Council Policy Statement (TCPS 2)**

The *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, commonly known as TCPS 2 (Canadian Institutes of Health Research et al., 2022), is the prevailing Canadian standard for ethical research involving humans. Respect for human dignity, the underlying value of the TCPS 2, is expressed through the following three core principles:

- **respect for persons:** recognizing “the intrinsic value of human beings and the respect and consideration that they are due. It incorporates the dual moral obligations to respect autonomy and to protect those with developing, impaired, or diminished autonomy” (Canadian Institutes of Health Research et al., 2022, p. 277).

- **concern for welfare:** requiring “researchers and REBs should aim to protect the welfare of participants, and, in some circumstances, to promote that welfare in view of any
foreseeable risks associated with the research” (Canadian Institutes of Health Research et al., 2022, p. 8).

- **justice**: referring “to the obligation to treat people fairly and equitably. Fairness entails treating all people with equal respect and concern. Equity requires distributing the benefits and burdens of research participation in such a way that no segment of the population is unduly burdened by the harms of research or denied the benefits of the knowledge generated from it” (Canadian Institutes of Health Research et al., 2022, p. 272).

Institutions and REBs across Canada have adopted the *TCPS 2* even if they do not receive Tri-Agency funding. Those who devised the original *TCPS* in 1988, as well as ongoing additions to it (2010, 2014, 2018, 2022), fully recognize that the *TCPS 2* works in conjunction with other sources of guidance for research ethics, including professional bodies such as the Canadian Nurses Association (CNA) and the Canadian Medical Association. For example, the CNA developed specific research ethics guidelines for nurse researchers in French and English (1994, 2002), where they emphasized the need for extra care and attention when health care professionals are involved with human research. Now, all these different professional organizations’ guidelines have become part of the Tri-Council governance. In addition, the CNA *Code of Ethics for Registered Nurses* (2017), articulates the following research-related responsibilities as a part of providing safe, compassionate, competent, and ethical care:

10. Nurses support, use and engage in research and other activities that promote safe, competent, compassionate and ethical care, and they use guidelines for ethical research that are in keeping with nursing values.

11. Nurses who are involved in research respect the well-being of persons receiving care above all other objectives, including the search for knowledge. They pay attention to the safety of persons receiving care and to *informed consent*, the risk-benefit balance, the privacy and
Relevant Ethical Guidelines, Policies and Legislation

In Canada, research is governed primarily by ethical guidelines which do not have the force of law; this is unlike the legislative approach taken by some other countries, such as the United States and France. Researchers should apply the guidelines of the TCPS 2 in conjunction with relevant and applicable ethical guidelines, policies, legislation, and regulation. For example, research participants’ rights to privacy are legally protected by federal law (see Personal Information Protection and Electronic Documents Act, 2000) and provincial/territorial laws (see for example BC’s Personal Information Protection Act, 2003). Thus, researchers have the obligation to safeguard any information collected in the context of their study, to know what legislation is applicable, and to comply with it. Legal requirements related to consent and the decision-making capacity of participants are established at the provincial/territorial level, such as BC’s Health Care (Consent) and Care Facility (Admission) Act (1996). Another example applies to clinical trials research regulated under Health Canada’s Food and Drugs Act (1985). In addition, depending on the type of research and the source of funding, Canadian researchers can be subject to international ethical guidance such as the International Conference on Harmonisation Good Clinical Practice Guidelines (ICH-GCP) (n.d.) and foreign oversight bodies such as the United States Food and Drug Administration.

TCPS 2: A Living Document

Another important feature of TCPS 2 is that the policy is positioned as a “living document” and continues to be revised as new challenges are placed before REBs, researchers, and our society. Processes are in place to engage with Canada’s research community, to communicate interpretations of the TCPS 2, and to develop new guidance. For example, a very significant addition to the TCPS was realized in 2010 with a new chapter, “Research Involving the First Nations, Inuit and Métis Peoples of Canada” (Canadian Institutes of Health Research et al., 2022, pp. 146–182). This new Chapter 9...
reflected a growing awareness about the need to conduct and review research involving Indigenous people more respectfully, and with understanding of a community’s unique cultural traditions, customs, codes of practice, and worldview. Shawn Wilson (2008) describes research done “in a good way” as a sacred endeavour, grounded in respect and traditional wisdom, which leads to the support of community and creation of healing. The inclusion of Chapter 9 moves toward a “two-eyed seeing approach” (Bartlett et al., 2012; Bull, 2016) that incorporates both broad Indigenous principles (such as relational accountability, communality of knowledge, reciprocity, and benefit sharing [Kara, 2018; Wilson, 2008]) and core Western ethical principles (respect for persons, concern for welfare, and justice). In addition, TCPS 2’s Chapter 9 is intended to work with Indigenous-led ethical processes and protocols such as the First Nations Principles of OCAP (ownership, control, access, and possession) (First Nations Information Governance Centre, n.d.). Researchers can use the OCAP framework for guidance on how First Nations data should be collected, protected, used, or shared in a way that is beneficial and respectful to Indigenous communities. The release of the Truth and Reconciliation Commission of Canada’s final report (2015) reinforces the ongoing need for nurses to understand this new era of Indigenous research ethics.

Also in 2010, the term “participant” replaced “subject” in the TCPS to reflect an ideological departure from framing people as objects of study. In TCPS 2 (2022), participants in research are defined as “those individuals whose data, biological materials, or responses to interventions, stimuli, or questions by the researcher, are relevant to answering the research question(s)” (Article 2.1, p. 14). In 2018, new guidance included how to assess, manage, and review risks to communities, including situations where non-participants might be inadvertently exposed to a research intervention. TCPS 2 updates in 2022 include guidance on broad consent for the storage of data and human biological materials for future unspecified research, streamlining multi-jurisdictional research ethics review of minimal risk research, and research involving totipotent stem cells and human cell lines. The ongoing input of nurse researchers to the TCPS guidelines is essential in response to
societal, policy, and legislative changes, and related ethical challenges, and as new approaches of nursing inquiry are developed.

Research Ethics Education

The Panel organizes education in research ethics for the research community, such as the online tutorial *TCPS 2: CORE-2022 (Course on Research Ethics)* (Panel on Research Ethics, 2023b). The CORE-2022 applies to all research involving human participants, regardless of discipline or methodology, with a focus on the Canadian context. Prior to research ethics approval, most REBs require that researchers who engage in research with human participants (and their personal information) complete this tutorial. Upon successful completion, learners can obtain a CORE-2022 Certificate of Completion. We recommend that all readers who have not already done so take the time to explore this interesting four-hour course, available at no charge in English and French.

The Panel has also developed educational resources to assist people who are participating in research or are considering joining a study. These resources cover basic information about participation in research, specific information on topics such as privacy, risks and benefits, and consent, and how the ethics guidance in the TCPS 2 aims to provide protection for research participants. We encourage all readers to find opportunities to participate in research studies to gain valuable experience about what it is like to be a study participant.

Canada’s Research Ethics Boards

At the local level, the main body responsible for using the TCPS 2 are researchers, and to oversee their steadfastness there are REBs. The TCPS 2 sets out the following requirements for REB membership:

First, there must be at least five members, including both men and women, of whom at least

a. two members have expertise in relevant research disciplines, fields, and methodologies covered by the REB;

b. one member is knowledgeable in ethics;
c. one member is knowledgeable in the relevant law. That member should not be the institution’s legal counsel or risk manager. This is mandatory for biomedical research and is advisable, but not mandatory, for other areas of research; and

d. one community member has no affiliation with the institution. (Canadian Institutes of Health Research et al., 2022, Article 6.4, p. 97).

Additionally, Health Canada requires that “a majority of [REB members] are Canadian citizens or permanent residents” (Government of Canada, 1985, c.03.306). The majority of Canada’s universities and health care delivery organizations (hospitals, health networks/authorities) have, or are affiliated with, local REBs. In some cases, researchers use a centralized REB (e.g., Ontario Cancer Research Ethics Board), a harmonized process (e.g., Research Ethics BC), an independent REB, or a single ethics process across research and practice activities inclusive of research, quality improvement (QI), program evaluation, etc. (e.g., Public Health Ontario). As noted above, REBs follow the guidelines of the TCPS 2, as well as other relevant ethical guidelines, policies, legislation, and regulation that apply depending on the research project. In addition, REBs and communities have collaborated to develop specific guidelines and enact their own processes for research ethical review that are sensitive to types of research or local communities. Examples of community-led ethical guidelines are increasingly available in relation to research involving Indigenous peoples (Hayward et al., 2021). Examples of such guidelines include the National Inuit Strategy on Research (Inuit Tapiriit Kanatami, 2018), as well as research involving communities marginalized by society, such as Vancouver’s Downtown Eastside (Neufeld et al., 2019).

The Four Main Roles That Nurses Have Related to Research Ethics

The TCPS 2’s core principles—respect for persons, concern for welfare, and justice—align well with the seven primary values in the CNA Code of Ethics for Registered Nurses (2017):
• providing safe, compassionate, competent and ethical care
• promoting health and well-being
• promoting and respecting informed decision-making
• honouring dignity
• maintaining privacy and confidentiality
• promoting justice
• being accountable (pp. 8–16)

Nurses are often at the point of care and are important advocates for patients and families, and so frequently find themselves at the front lines of health care research. Consequently, nurses across the profession need a good working knowledge of how ethical principles apply in the research context, how research ethics processes work, and how to identify and respond to ethical issues in research. In this section, we use Ethics in Practice case studies to explore the four main roles that nurses have related to research and some of the ethical issues that can arise: (1) as care providers (2) as managers and leaders (3) as researchers and research coordinators, and (4) as serving REB members. We give examples of how the core ethical principles and primary nursing values can be put into practice. Parts of this section were adapted from Chapter 14, written by Oberle & Storch (2013), in the second edition of Toward a Moral Horizon: Nursing Ethics for Leadership and Practice (Storch et al., 2013) and the CNA Ethical Research Guidelines for Registered Nurses (2002).

1. Nurses as Care Providers

Nurses working in organizations, and across all levels of practice, may be involved in a variety of activities, including research, quality improvement (QI), and program evaluation, to improve care and services (Faden et al., 2013). Nurses may be direct care providers for patients (clients, residents) and families, and may, at times, be research participants themselves, or researchers. The obligations of the nurse in these diverse roles may present ethical challenges. The practice/research distinction that began with the Belmont Report is founded on the belief that in clinical practice, patients’ immediate interests are addressed because health care professionals are obligated to care for individual patients in a way that is personalized
to benefit each patient via standard care. On the other hand, in research activities, study participants are subjected to potential risks of harm for the benefit of future patients, the larger population, and/or to further the researchers’ or institutions’ goals. At times, the boundary between clinical care and clinical research is blurred, such as in cancer care (Kass et al., 2013). Likewise, boundaries between health care improvement/evaluation and research activities can also be unclear.

With regards to the harmony between research and practice, nurses require an understanding of such things as: what research is going on in their area; if patients (or their legal health care representatives) understand the nature of the studies they have voluntarily consented to participate in; if they (as nurses) are required to carry out research procedures; and how research project requirements fit into their other nursing responsibilities. If nurses find any elements of the research conducted in their workplaces troubling, these concerns should be voiced to researchers, nursing managers, or the REB. Each nurse is accountable for their own practice. This is not to suggest that it is easy—speaking up requires considerable moral courage and excellent communication skills.

**ETHICS IN PRACTICE 2-1**

**Identifying Potential Harm for Research Participants**

Jeremy is a clinical nurse specialist at a long-term care facility. He notices that Hao-Yu, one of the residents for whom he is caring, has become extremely disoriented over the past few days. Hao-Yu is usually a sound sleeper, but has been wandering at night. During the day, his appetite has diminished and he has lost interest in joining social activities. Jeremy checks Hao-Yu’s chart and notices that he was enrolled in a clinical trial for an investigational diabetes drug. Hao-Yu began taking the study drug ten days ago. Jeremy has concerns that the research might be jeopardizing Hao-Yu’s welfare. He makes a note in Hao-Yu’s chart and decides to leave a voicemail for the research coordinator to determine if the study drug could be contributing to the changes in Hao-Yu’s orientation (TCPS 2 guidance on *Safety Monitoring in Clinical Trials*). Jeremy also wonders if it would be a good idea to inform Hao-Yu’s daughter-in-law, who is his health care representative, but he knows that she’s busy with her job and young children (TCPS 2 guidance on the *Consent Process*). Before calling the family, Jeremy takes time to discuss Hao-Yu’s situation with the nurse in charge.
ETHICS IN PRACTICE 2-2

Applying an Ethical Approach to All Learning Activities

As the nurse practitioner (NP), manager, and nurse leader of a busy urban emergency department (ED), one of Chris’ roles is overseeing and providing operational approval for all learning projects. Projects deemed to constitute “research” also require research ethics approval. A group of staff from another department approach Chris because they want to implement an intervention to help ED staff better manage aggressive behaviour in patients brought to hospital by police or ambulance. To help the team determine if the project is research or QI and to answer their question if consent is required from staff and/or patients, Chris directs the team to the ARECCI Screening Tool (Alberta Innovates, 2017) to learn: (a) the level of risk of their project (b) the types of ethical risks and concerns and (c) the appropriate type of ethics review (REB or internal organizational review). The team completes the ethical screening and prepares to submit their project to the REB. The project lead schedules a meeting with Chris to discuss the study protocol, which involves researchers shadowing patients to observe what happens when things go wrong in the ED. Chris suggests that having researchers shadow patients who are already in vulnerable circumstances could interfere with the important trust-building needed to ensure the highest quality of care. The team appreciates this input and revises their study protocol to incorporate a trauma-informed practice lens and to shadow clerical, medical, and nursing staff instead of patients.

REFLECTIVE QUESTIONS

1. How is Jeremy in a position to protect his patients/residents from harm and to promote their well-being when they are involved in research studies?

2. How can Jeremy ensure that his patients/residents (and possibly their families) understand the nature of the study they are enrolled in, and that their consent is fully informed, voluntary, and ongoing? What organizational support does Jeremy need to do this?
2. Nurses as Managers and Leaders

Nurses may be managers and leaders in organizations where there is an ongoing range of learning activities including research, QI, and program evaluation to improve care and services. Frontline nurse managers and leaders are responsible for assessing and managing nursing workload and quality of care, ensuring a positive work environment, fostering a moral climate, and managing unit budgets.

Research activities can have an impact on all of these areas, and in many institutions, operational approval by nurse managers or leaders is required before a researcher is permitted to bring a study into the organization. Before providing that signature, the manager has a responsibility to become familiar with the protocol, ask any questions that arise, and await satisfactory answers provided by the researcher. If there is no operational approval requirement for research within an institution, managers should be prepared to seek a change in organizational policy. Part of that policy should include an outline of responsibilities of nurse managers and staff nurses in regard to research activities; statements about workload and funding issues; and requirements for nursing support, including education. Organizations should not be silent on such matters, as failure to address such issues can place patients, their families, and nurses at unnecessary risk and cause undue stress.
3. Nurses as Researchers and Research Coordinators

Advanced Practice Nurses (APNs) may be principal investigators or co-investigators in their own studies, and nurses at all levels of practice may work as research assistants or research coordinators for other health care research studies. REBs generally provide research teams with comprehensive procedural guidance and direction on determining, first of all, if a research project requires REB review (TCPS 2 guidance on Scope of Research Ethics Review). Such guidance is helpful to research teams preparing a submission to the REB. The research protocol, the document that describes the overall planning of a study, is a critical component of an REB application. Research protocols generally include a comprehensive description of each of the following elements:

- background and rationale
- objectives
- methods
- recruitment of human participants
- informed consent/assent
- potential harms and benefits to participants, families, and communities
- privacy and confidentiality
- knowledge translation and dissemination plan
- budget, potential biases and limitations
- other considerations where relevant (e.g., multijurisdictional research; sex and gender)

Appendix 2-1 summarizes the key considerations when writing research proposals. Individual REBs typically provide guidance on what information should be covered in each section of a research protocol. For example, Health Canada’s REB (Health Canada, 2022) provides a helpful summary of key considerations. We advise applicants preparing an REB submission to follow the directions carefully to ensure their research protocols provide sufficient ethical and methodological detail so that the REB can assess the proposal. The protocol must be written in order that each REB
member (even those members who are not experts in the field of the research) will be able to understand the research.

A complete research submission includes related documents such as questionnaires, interview scripts, recruitment materials, and consent and assent forms. Informed consent for research also involves processes that need to be established for the research to begin. Key areas to be included in an informed consent discussion include: (a) protection of confidentiality (b) knowledge of the processes involved (c) understanding about any discomforts and inconveniences, foreseeable risks and costs, and (d) any benefits and compensation provided (Kluge, 2013). Some REBs provide checklist tools to help identify required regulations, guidelines, and policies to ensure all applicable elements are present in the study documents. At times, the REB requests that the researcher (or principal investigator) present to the REB or answer questions. A research project cannot begin until the REB has given full unconditional approval. However, in some areas of research, and particularly the qualitative paradigm, the process of gaining entry (the ethical and academic processes the researcher undertakes to access and engage with research participants and the broader professional and institutional community) can blur the lines of when research data is collected. The TCPS 2 chapter on Qualitative Research is helpful in this regard.

Once a research project is approved and underway, reflexivity is an integral part of the process of rigorous inquiry that involves researchers being able to be critically reflective of the research process they are engaged in. As noted by Australian ethicists Marilys Guillemin and Lynn Gillam (2004),

Being reflexive about research practice means a number of things: first, an acknowledgment of micro-ethics, that is, of the ethical dimensions of ordinary, everyday research practice; second, sensitivity to what we call the “ethically important moments” in research practice, in all their particularities; and third, having or being able to develop a means of addressing and responding to ethical concerns if and when they arise in the research (which might well
Toward a Moral Horizon

ETHICS IN PRACTICE 2-3

Balancing Conflicting Ethical Duties

Binder is an NP and researcher who is studying the experience of new mothers who are breastfeeding. She visits research participants in their homes, observes how the infants latch, and helps the mothers learn how to use a breastfeeding pump. Due to the COVID-19 pandemic, postpartum NPs and public health nurses are engaged in contact tracing and vaccine clinics. During a study visit, Binder assists Sara with breastfeeding as they chat about latching technique. Suddenly, Sara begins to sob and confides that her partner is abusing her six-year old son. Binder is surprised, but quickly shifts into counsellor mode, comforts the baby, and listens. Binder is aware that this is an “ethically important moment” because Sara was told that her information would be kept confidential in the study, yet provincial legislation requires mandatory reporting of child abuse. Nothing in the consent form addressed a situation such as this. Binder considers her conflicting ethical duties: to keep Sara’s disclosure in confidence or to report the abuse for fear that Sara’s son is at risk of harm (TCPS 2 guidance on the Ethical Duty of Confidentiality). Before she leaves Sara’s home, Binder and Sara talk about a safety plan for her and children. Binder immediately seeks guidance from her colleagues, her professional regulatory body, and the REB to find ways to report the abuse in a way that is sensitive to the interpersonal and ethical aspects of the research relationship.

REFLECTIVE QUESTIONS

1. Besides the obvious ethical issue about whether Binder is ethically required to breach Sara’s confidentiality, what immediate ethical concerns was Binder faced with involving if and how to respond to what Sara told her?

2. How might the practice of reflexivity help Binder to process and learn from Sara’s surprising disclosure?

include a way of preemting potential ethical problems before they take hold). (p. 276)
4. Nurses as REB Members

Finally, APNs may be members of REBs. Serving on an REB is an important role for advanced practice nurses to consider, both to learn more about the work of assessing research in line with the TCPS 2 and to add safeguards of local significance. Both authors of this chapter have served on REBs and consulted with REBs. We have found REB service to be a good way to learn and keep abreast of the TCPS 2 guidelines while also developing knowledge in new areas of practice and research. Because APNs serving on an REB have a breadth of experience in nursing practice, they are normally the first to pick up on research measures that would be difficult or contraindicated for patients/families or other potential participants (such as staff). Nurses are also often more sensitive to the patient and family experience of the research.

Research involving humans can be ethically justified only when the research is scientifically sound, the potential benefit significantly outweighs the potential for harm, there is an adequate process for informed consent (assent where applicable), and there is justice or fairness in the selection of participants. For example, Health Canada’s REB (2022) provides a useful summary of key considerations when reviewing research proposals to assess whether a proposal meets the ethical requirements for research involving humans, including

- methodology (e.g., if the study is likely to produce valid results)
- selection and recruitment (e.g., based on sex, gender, age, ethnicity, and language)
- informed consent process (e.g., voluntariness, capacity, and comprehension)
- potential harms and benefits, and how these are distributed
- privacy and confidentiality (e.g., highly sensitive information, identifying information, biological samples), and
- any real, apparent, or potential conflicts of interest that may affect how the research is conducted

An ill-designed study is a waste of resources (time, funding dollars, personnel) and possibly participants’ goodwill—and is therefore
unethical. Appendix 2-1 summarizes the key considerations when reviewing research proposals.

**ETHICS IN PRACTICE 2-4**

*Advancing Nursing Inquiry*

Danielle, a nurse educator in a community hospital, is an advocate of interprofessional research in the hospital. She conducts her own research and has mentored research teams, most of which include graduate nursing students and patient representatives. Danielle has been asked to serve as a member of a nearby university’s REB, which to date has mostly reviewed clinical trials. At one of the first REB meetings she attends, Danielle observes the members having difficulty reviewing a study using interpretive description, a qualitative methodology developed in the nursing profession by Sally Thorne from the UBC School of Nursing. In particular, the REB members seem puzzled with the vague description of sample size in the protocol. Danielle realizes that her REB colleagues lack familiarity with nursing research methodologies. She then proceeds to appraise the study application on the basis of her knowledge about how emergent research works in the field and ethical concerns that could arise, based on the TCPS 2 chapter on *Qualitative Research*. The REB Chair expresses their gratitude to Danielle, and requests that she provide an education session on nursing inquiry to all REB members.

**REFLECTIVE QUESTIONS**

1. *In what ways did Danielle, as a nurse educator and advanced practice nurse leader, contribute constructively to the REB’s discussion and promote working as an effective team?*

2. *As an REB member, what should Danielle do if she is assigned to present a research protocol, but lacks confidence about her knowledge? For example, if she is unfamiliar with the small community that is the study population of interest, or if she is unsure about the requirements of the research methodology?*

**Research Ethics on the Moral Horizon: Vigilance Must Be Ongoing**

In this chapter, we have reviewed key events in the recent era of Euro-Western research ethics. We have outlined respect for persons, concern for welfare, and justice, as the core principles of the TCPS 2. We have discussed the role and function of research ethics boards in Canada and provided examples of how the TCPS 2,
Canada’s standard for ethical research, works in conjunction with other codes, legislation, and guidelines. In addition, we have identified four key roles for advanced practice nurses in promoting ethical research and provided examples of ethical issues that can arise in each of these areas.

Nurses must be vigilant when it comes to research ethics. Unfortunately, despite more than half a century’s evolution of bioethics and research ethics oversight, it is clear that health care ethics-related transgressions are not a thing of the past. At this time, we have noted three violations of health care ethics and human rights recently reported:

- Lipphardt et al. (2021) identified concerns with how researchers analyzed the genetic data of marginalized populations via public DNA databases, focusing on implications for Roma people.
- In April 2022, Health Canada announced a review of all trials involving methylenedioxymethamphetamine (MDMA, also known as “ecstasy”) to ensure patient safety and compliance with regulations (Lindsay, 2022).

As information is uncovered—and as societal attitudes, norms and ethical awareness evolve—new accounts of abuse of research participants and scientific misconduct (such as data falsification, data fabrication, or plagiarism [Marcus & Oransky, n.d.]) continue to be revealed (Emanuel et al., 2008; Pimple, 2017; Resnick, 2018). For these reasons, we urge nurses to advocate for the appropriate representation of, and collaboration with, diverse and historically underserved populations in research, and to consider the perspectives of research participants. In this chapter, we have underscored the active and critical roles that those in the nursing profession—and particularly advanced practice nurses—play in protecting the rights and welfare of patients and research participants while advancing the pursuit of knowledge.
QUESTIONS FOR REFLECTION

1. What kinds of guidelines are in place in your workplace to guide nurses’ involvement in research?

2. Why might there be gaps between what you think nurses ought to do in research-related situations, what nurses believe they ought to do, and what nurses actually do?

3. What kinds of research-related issues have you encountered in your practice, and what action have you taken?

4. What kinds of opportunities do advanced practice nurse leaders have to promote ethical research in ways that:
   - uphold the primary values in the nursing profession?
   - increase collaboration with diverse and historically underserved populations?
   - better align with diverse community values/needs and broader societal goals, such as Indigenous reconciliation and social justice?


APPENDIX 2-1

Key Considerations for Writing and Reviewing Research Proposals
<table>
<thead>
<tr>
<th>TOPIC</th>
<th>RELEVANT QUESTIONS</th>
</tr>
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<tbody>
<tr>
<td><strong>Background and Rationale</strong></td>
<td>To ensure that the study is important, merits participants' time, and generates important knowledge.</td>
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<tr>
<td></td>
<td>- Is there evidence that the study is necessary and important?</td>
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<tr>
<td></td>
<td>- Is there evidence that the right questions are being asked?</td>
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<td></td>
<td>- Is there evidence that the approach used is appropriate?</td>
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<tr>
<td><strong>Study Objectives</strong></td>
<td>To ensure that the study is feasible and reasonable.</td>
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<td></td>
<td>- Are the objectives of the study reasonable and manageable given previous work in the area?</td>
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<td></td>
<td>- What are the expected outcomes and knowledge of the study?</td>
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<tr>
<td><strong>Methods</strong></td>
<td>To ensure that the study is scientifically sound and results are likely to be valid and meritorious.</td>
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<tr>
<td></td>
<td>- Do the research methods seem appropriate to the question?</td>
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<td></td>
<td>- Is the study likely to produce valid results?</td>
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<td></td>
<td>- What, where, how, on whom, and when will the study take place?</td>
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<td></td>
<td>- What types of biological samples will be collected, and will genetic testing be conducted?</td>
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<td></td>
<td>- How will samples/data be used and analyzed?</td>
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<tr>
<td><strong>Sample and Recruitment of Human Participants</strong></td>
<td>To ensure that there is justice or fairness in selection of participants, and participants are recruited appropriately.</td>
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<tr>
<td></td>
<td>- Is the sample appropriately delineated?</td>
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<tr>
<td></td>
<td>- Are appropriate inclusion criteria present?</td>
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<tr>
<td></td>
<td>- Is any population excluded inappropriately (e.g., based on sex, gender, age, ethnicity, language)?</td>
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<tr>
<td></td>
<td>- Are people in the sample vulnerable in any way?</td>
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<td></td>
<td>- What has been done to protect potential participants from harms? From feeling coerced?</td>
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<tr>
<td></td>
<td>- Is there evidence of undue inducement to accept more than minimal risk?</td>
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<tr>
<td></td>
<td>- What recruitment strategies and materials are to be used?</td>
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<tr>
<td>TOPIC</td>
<td>RELEVANT QUESTIONS</td>
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</table>
| Informed Consent/Assent   | • Is there evidence that elements of informed consent/assent (voluntariness, capacity, and comprehension) will be present?  
                           | • Are alternatives to participation outlined (for therapeutic studies)?  
                           | • Are consent and assent documents written in plain language?  
                           | • Are the required elements of consent (as outlined by TCPS 2 and institutional policy) present?  
                           | • Will consent be oral or written?  
                           | • Is there a justified request for authorized representatives if appropriate?  
                           | • Is there a justified request for waiver of consent if appropriate? |
| Potential Harms and Benefits | • Are potential (known and reasonably anticipated) harms and discomforts adequately described?  
                           | • Are possible benefits described appropriately (in other words, not overstated)?  
                           | • Have appropriate measures being taken to maximize benefit and minimize harm?  
                           | • What happens if participants become injured or get sick as a result of being in this study?  
                           | • Have any rights to legal recourse been waived? |
| Privacy and Confidentiality | • What types of personal information about participants will be collected (e.g., highly sensitive information, identifying information, biological samples)?  
                           | • What personal information about participants will be disclosed, to whom (e.g., study sponsor, Health Canada, REB), and why?  
                           | • How will personal information be protected (e.g., coded), how long will information be kept, and how/where will it be stored?  
                           | • What happens to information/samples if participants wish to withdraw their consent? |
| Knowledge Translation and Dissemination | • Will participants and their communities receive and benefit from the results of the research? |
### TOPIC

#### Budget
To ensure that there is adequate funding to conduct the research and potential biases and limitations are identified.

- Is the budget appropriate? Are expenses of the study clearly laid out?
- Are expenses to be assumed by appropriate bodies? For example, who pays for extra diagnostic tests?
- Are participants to be compensated for out-of-pocket expenses?
- Is there evidence that the investigator might benefit inappropriately (i.e., is there a suggestion that the researcher is being paid to recruit participants, and could this then lead to inappropriate recruitment?)
- Are there any real, apparent or potential conflicts of interest that may affect how the research is conducted?

#### Other Considerations
For some research studies, other areas may need to be addressed, such as:

- Multicentre or multijurisdictional research
- Sex and gender
- Official languages
- Indigenous research
- Community engagement
- Legislation and regulations

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THE PROVISION OF HEALTH CARE in any country is influenced by economic, political, social, and cultural forces. While there are clearly many influences on the structures of all social programs, as Canadians, our values determine how we frame problems in health care and the solutions we endorse or reject (Kenny, 2002). Publicly funded health care in Canada has been a source of pride, is held up as a reflection of Canadian values of equity and solidarity, and involves sharing burdens and benefits (Beauchamp & Steinbock, 1999; Pauly & Storch, 2013). As Villeneuve (2017) stated, numerous
studies, debates, and agreements show that Canadians value accessibility to health care without out-of-pocket payment. While the Canadian health care systems that are in place nationwide are not perfect, the ethics of caring for one another continues to be sustained as an espoused social value by a majority of Canadians (Martin et al., 2018; Nixon et al., 2018; Storch & Scaia, 2019).

It is important for advanced practice nurses (APNs), and all nurse leaders, to understand how Canadian health care is delivered, as well as the associated challenges with service delivery, in order to guide those seeking care, assist persons already receiving care, and help those wishing to reform health care systems to know how they can be involved. APNs need a firm understanding of the origins, development, and trajectory of Canadian health care systems in order to wisely debate health care issues, and, where needed, be agents of change in health care structures and processes.

In this chapter, we begin with a focus on the manner in which health care delivery is structured in Canada, with particular attention to federal, territorial, and provincial responsibilities. We provide a brief overview of the history, financing, and delivery of Canadian health care, and explicate underlying values captured in key principles that have provided direction for the development and provision of health care in Canada. Limitations and challenges of publicly funded health care in Canada are also discussed. Some of the current limitations and challenges are linked to the historical development of Canada’s health care systems, and include deficiencies in a number of areas, such as long-term care (LTC), care of the mentally ill, and health care for Indigenous people. Other growing and pressing contemporary deficiencies are evidenced by the increasing number of Canadians who lack access to a primary caregiver, and the many Canadians who are unable to obtain timely access to emergency, medical, and surgical services. Throughout the COVID-19 pandemic, there has been a major shortage of health care providers (primarily nurses and physicians), resulting in a further lack of access to primary and acute care, thus further broadening the portrait of an eroding system of care. Over time, privatization of health care services and extra-billing have been promoted by some as a way to address the limitations of the publicly funded health care system. We briefly discuss these approaches as a
way to address access to health care. We conclude the chapter by examining the role of leaders in nursing in addressing health care system challenges, with specific attention to the role of advanced practice nurse leaders.

**Division of Federal, Provincial, and Territorial Responsibilities**

One way to reflect upon Canadian health care is to examine how it was “built,” and how federal, provincial, and territorial goals were harmonized over time. Speaking about Canada’s health care system as one system is inaccurate, since Canada is a federation of 13 provinces and territories, each with a different health care system (Fierlbeck, 2011). Contrary to what the public might assume, provincial and territorial authorities—not the federal government—have managed the development and deployment of most health services, and continue to do so today.

Fierlbeck (2011) defined the Canadian health care system as “a fragmented system controlled by the provinces but coordinated by the federal government with the provinces’ consent” (p. 18, emphasis in original). Villeneuve (2017) pointed out that “it is important for nurses and other students of public policy to understand from the outset that Canada’s provinces do not report in some hierarchical way to the federal government” (p. 41). As an example of this, there was fragmentation during the COVID-19 pandemic, with officials in each province and territory stipulating the rules in their individual jurisdictions about the wearing of masks, vaccine administration, rapid testing, and other directives related to the global pandemic.

Canada’s founding legislation, the *Constitution Act, 1867* (originally known as the *British North America Act* (*BNA Act*)), set out the division of federal and provincial responsibilities, with particular attention to health care. Historically, there was considerable debate among federal and provincial governments, eventually culminating in reasonable decisions about the division of responsibilities. Specific duties for all provinces were described in section 92 of the *Constitution Act*. The *Act* gave provinces exclusive powers for “the establishment, maintenance, and management of
hospitals, asylums, charities, and eleemosynary institutions (i.e., supported by or dependent on charity institutions) in and for the province other than marine hospitals” (Aucoin, 1980, p. 244). Each province was also given the right of direct taxation within its boundaries in order to raise revenue for provincial purposes, and they were to attend to all matters of a local and private nature in the province or territory.

The federal government’s powers under the Constitution Act were limited to the raising of money through a system of taxation, conducting the census and maintaining statistics, providing for quarantine and the establishment and maintenance of marine hospitals, and overseeing Indigenous lands reserved for Indigenous Peoples (Aucoin, 1980, p. 244). It should be noted here that the lack of inclusion of Indigenous people in Canada-wide planning for hospitals, asylums, and Indigenous lands has had serious ongoing repercussions.

Throughout the development of the health care systems, both levels of government attempted to develop programs that did not violate the powers which had been assigned to them in the Constitution Act. Initially, these arrangements seemed workable. However, as Aucoin (1980) noted, “the largest portion of these financial outlays was paid to provincial governments in order that they might finance health care schemes in their provinces,” but in doing so the federal government “exercised considerable leverage in determining the purposes for which these allocated funds could be spent,” including “determining the kind of research which would be supported in the sciences on which modern health care was based” (p. 245). Thus, the federal government gradually began to have a greater say in how the provinces were using health care finances.

Activities of the Federal Government

Underlying values evident in determining Canadian priorities are the fundamental commitments to “peace, order and good government” in our constitutional framework, relative to the fundamentally different US constitution of “life, liberty and the pursuit of happiness” (Villeneuve, 2017, p. 27). In the Constitution Act, matters regarding social welfare were described as both local and
private, and thus under the clear jurisdiction of the provinces (Rice & Prince, 2000). However, the Great Depression of the 1930s “left no doubt in the minds of Canadians that social conditions rather than individual behaviors determined the fate of most families” (p. 14). To extend that insight, the federal government commissioned a report called Social Security for Canada, commonly known as the Marsh Report (1943), in which programs were recommended, then developed, “to help people deal with problems created by modern industrial society” (Rice & Prince, 2000, p. 15).

Unfortunately, the federal government did not include Indigenous people in any determinations regarding social programs, and, as a result, there were tragic consequences for Indigenous communities. For example, the Canadian government developed a policy “to remove children from Aboriginal families and place them in residential schools in an effort to assimilate them into the majority culture of people who settled on Aboriginal lands” (Villeneuve, 2017, p. 9). We now know that “much of the treatment of those children in many residential schools … was cruel to the point of being inhuman” (p. 9), and numerous unexplained deaths of children occurred. In addition, discrimination against Indigenous women became more visible. In fact, “Canada was admonished by the United Nations in 2015 for its ‘grave violation’ of human rights by failing to take on the disproportionate levels of violence against Aboriginal women” (Villeneuve, 2017, p. 9). Indigenous leaders and federal, provincial, and territorial governments have been engaged in ongoing dialogue, discussion, and investigations about these violations and their outcomes, attempting to find a way forward (Truth and Reconciliation Commission of Canada [TRC], 2015).

As a result of the Great Depression in the 1930s, Canadians began to see social policies as necessary to uphold their lives and their work. Several post-World War I pensions and other programs to aid returning soldiers were offered, leading to the introduction of the Old Age Pensions Act in 1927 (Rice & Prince, 2000, p. 45), which became a long-standing program. In Table 3-1 below, we outline the major federal legislation passed between 1867 and 1985 which influenced the evolution of the Canadian health care system.
Provincial and Territorial Government Actions

In 1947, the federal government developed a series of national health grants to be provided to each province and territory. The grants included a health survey grant, followed by a series of other grants for public health, venereal disease control, mental health, tuberculosis control, cancer control, children with disabilities, public health research, hospital construction, and professional training (Taylor, 1987). These grants were intended to assist the provinces and territories in building their health services and infrastructure (Rice & Prince, 2000). The grants were followed by grant packages that included funds for health planning, public health, hospital construction, professional training, as well as other basic services. The grants were offered with the understanding that each province or territory was free to decline the offer of any and all grants (Hastings, 1980).

Subsequent developments in several provinces set the stage for the uptake of new approaches. The fundamental value of caring for people in need of health care, without out-of-pocket cost, is credited to Premier Tommy Douglas and officials in the province of Saskatchewan, who were committed to ensuring that everyone should have free access to health care (Taylor, 1987). Douglas became aware of the need for all people to have free access to health care when, as a child, he needed privately offered and costly care (Margoshes, 1990). His experience, and the plight of others, caused him to argue, as summarized by Fierlbeck (2011), that “health care

<table>
<thead>
<tr>
<th>Date</th>
<th>Name of Federal Legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1867</td>
<td><em>Constitution Act</em> (formerly <em>British North American Act</em> [BNA Act])</td>
</tr>
<tr>
<td>1927</td>
<td><em>Old Age Pensions Act</em></td>
</tr>
<tr>
<td>1947</td>
<td>National Health Grants</td>
</tr>
<tr>
<td>1957</td>
<td><em>Hospital Insurance and Diagnostic Services Act</em> (HIDS Act)</td>
</tr>
<tr>
<td>1966</td>
<td><em>Medical Care Insurance Act</em> (Medicare)</td>
</tr>
</tbody>
</table>

**TABLE 3-1**

*Timeline of Federal Legislation Affecting Health Care, 1867–1985*

Toward a Moral Horizon
ought to be built on a recognition of human dignity, as well as a framework of economic efficiency” (p. 18).

Saskatchewan, with Douglas as premier, became a leader in the provision of province-wide health services and other notable innovations. For example, the Act outlining Saskatchewan’s hospital insurance plan received royal assent on April 4, 1946 and was implemented on January 1, 1947. It served as a model for the development of the federal Hospital Insurance and Diagnostic Services Act (HIDS Act) in 1957 (Taylor, 1987). As Taylor noted, “A social idea had been translated into an operating reality: the first universal hospital insurance program in North America had been launched. For Saskatchewan there was no turning back” (p. 103). In 1961, Saskatchewan added a public insurance plan for payment of physician services, which became a model for the federal Medical Care Insurance Act (Medicare) in 1966.

After Douglas helped establish the first universal health care programs in Canada, he stepped down from his role as Premier of Saskatchewan to lead the newly formed federal New Democratic Party (NDP), which became a successor to the national CCF (Cooperative Commonwealth Federation). In 1961, Douglas was elected the NDP’s first federal leader, and “in order to signal the primacy his government would allocate to health services, he also assumed the portfolio of health minister” (Taylor, 1987, p. 86).

Launching Medicare legislation (1966) was not without incident. As Douglas laid out plans for universal medical insurance, physicians’ strong opposition to the compulsory nature of the plan (which replaced fee-for-service with government payment to physicians) grew. For three weeks, 90% of physicians withdrew their services in reaction to what they perceived as “socialized medicine” (Villeneuve, 2017, p. 83). The standoff ended when the government agreed that physicians could opt out of Medicare.

As a result of the Medicare legislation, each province had to “buy in” to a program of hospital and diagnostic services insurance, then medical care insurance, to create and become part of Canada’s “universal” health care system. Thus, these two programs covering hospital insurance and medical insurance could only come into existence by agreement with each province, in order to avoid violation of the federal-provincial legislated rights.
Major Federal Legislative Action

Two significant federal programs came about with passage of the *HIDS Act* in 1957, and the *Medical Care Insurance Act* in 1962. Taylor described the *HIDS Act* as “an historic measure…. It was the largest governmental undertaking since the war and would require federal-provincial cooperation on a scale never known” (Taylor, 1987, p. 230). In fact, in the early 1960s Prime Minister John Diefenbaker became anxious about health care costs, calling for a review of the system and appointing the Honorable Justice Emmett Hall to undertake this review (known as the *Hall Commission*) (Villeneuve, 2017).

Most of these legislative innovations were first adopted by the remaining provinces, then adopted at the national level. Notably absent then, and still needed now, was adequate funding and coverage for two major programs: a program for Pharmacare (Fierlbeck, 2011), and funding for long-term care. These programs continue to be under discussion for inclusion as insured services under the *CHA*.

In relation to Pharmacare, Fierlbeck (2011) noted that both federal and provincial governments were concerned about offending pharmaceutical companies, “recognizing that when they are seen as good corporate citizens by governments (providing jobs, taxes and publicity) there is much less willingness to step on their toes by implementing a program that would disadvantage such strategic corporate allies” (p. 159). However, a national Pharmacare program could have been cost-saving for the government and beneficial for the public.

Commencing in 1961, Justice Emmett Hall was appointed by the Diefenbaker government to chair a national commission to inquire into facilities and services that had been developed, and to forecast future needs for health services for Canadians. He was also to recommend what steps should be taken, consistent with the division of legislative powers in Canada, to develop the best possible health services accessible to the Canadian people (Villeneuve, 2017, p. 83).

Villeneuve (2017) noted that nurses were particularly politically active during the 1960s and that the Dean of Nursing at the University of Montreal and past president of the Canadian Nurses
Association (CNA), Alice Girard, was a sitting member of the Hall Commission. The CNA, on behalf of Canadian nurses, presented a brief to the Commission containing twenty-five recommendations to improve nursing services and enhance Canada's health care systems.

The *Medical Care Insurance Act* and the *HIDS Act* eventually led to the development of the *Canada Health Act* (1985). When the two Acts were combined, the four principles that were meant to govern health care were established as part of the *Canada Health Act*. Later, a fifth principle was added. Thus, the *Canada Health Act* eventually included five principles which remain central to Canadian health care: public administration, comprehensiveness, universality, portability, and accessibility (Fierlbeck, 2011; Villeneuve, 2017). We will elaborate further about these principles in the section “The *Canada Health Act*.”

**Federal and Provincial Planning and Evaluation of Health Care Delivery**

During the period spanning 1964 to 2002, several key provincial processes were underway to study provincial health care provisions and systems. Four significant federal reports were also developed; these provided national guidance in key areas of health care. The reports are listed in Table 3-2 below and will be discussed briefly.
Since these reports influenced further developments in health care, a brief synopsis of each report is provided below.

- Provincially, Quebec led the way in completion of the *Commission of Inquiry on Health and Welfare* (1970), also known as the *Castonguay Report*. Developed over a six-year period, it was a broad inquiry into an income, health, and social security system for Quebec. This extensive report was

### TABLE 3-2

**Key Federal and Provincial Reports by Year and Province**

<table>
<thead>
<tr>
<th>Year(s)</th>
<th>Province</th>
<th>Name of Report</th>
</tr>
</thead>
</table>
  • *Royal Commission of Health Services: Vol. II. Dec 7, 1964*  
  • *Hall Commission* |
| 1970 | Quebec | • *Commission of Inquiry on Health and Welfare in Quebec*  
  • *Castonguay Report* |
| 1972 | Manitoba | • *White Paper on Health Policy* |
| 1972 | Federal | • *Report of the Community Health Centre Project*  
  • *Hastings Report* |
| 1973 | British Columbia | • *Health Security for British Columbia*  
  • *Foulkes Report* |
| 1974 | Ontario | • *Ontario Health Planning Task Force*  
  • *Mustard Report* |
| 1974 | Federal | • *A New Perspective on Health of Canadians*  
  • *Lalonde Report* |
| 2002 | Federal | • *The Standing Senate Committee on Social Affairs, Science and Technology Study on the State of the Health Care System in Canada*  
  • *Kirby Report* |
| 2002 | Alberta | • *A Framework for Reform: Report of the Premier’s Advisory Council on Health*  
  • *Mazankowski Report* |

**Provincial Reports**

Since these reports influenced further developments in health care, a brief synopsis of each report is provided below.
six years in the making, comprising seven volumes and numerous appendices, and has had lasting significance in Quebec.

- Manitoba published a *White Paper on Health Policy* in July 1972, which was designed for discussion with the public and health care professionals, and used to foster integration of activities within its seven regions. In the report, there was a call for combined community health and social service centres to be set up within districts.

- In 1974, Ontario embarked on a study (called the *Mustard Report*) to develop a comprehensive health plan for the Province of Ontario. The establishment of District Health Councils and Area Boards within the Councils to coordinate institutional management, primary health groups to provide continuous complete care, and secondary care groups to provide specialist services were recommended.

- Within the *Foulkes Report* (1973) in British Columbia, there was a call for the establishment of seven regions with local boards to have independence and autonomy, and for public health nurses to be classified as “physician associates” who would have a major role in coordinating care.

- Within Alberta’s *Mazankowski Report* (2002), there was an emphasis on new public management, which was essentially a clear commitment to move towards more market-oriented reforms. Fierlbeck (2011) noted that in both Alberta and Quebec, where there were proposals to privatize health care, those “proposals … were quickly shelved since there was public opposition” (p. 66).

**Federal Reports**

Meanwhile, the writers of two significant federal reports—a *New Perspective on the Health of Canadians*, known as the *Lalonde Report* (1974), and *The Community Health Centre in Canada*, known as the *Hastings Report* (1972)—urged a shift to less expensive community care to facilitate health promotion, disease prevention, and foster community action. Marc Lalonde, the Canadian
Minister of National Health and Welfare in 1974, “recognized that what usually are called health services are really sickness or treatment services” (Gellman, et al., 1980, p. 281). Lalonde (1974) concluded that

Marvelous though health care services are in Canada in comparison with other countries, there is little doubt that future improvements in the level of health of Canadians lie mainly in improving the environment, moderating self-imposed risks and adding to our knowledge of human biology. (p. 18)

The authors of these reports all described the engagement of professionals and the public in debates about their findings. Most of the reports contributed to federal, provincial, and territorial health care priorities and planning.

Two additional federal reports particularly worthy of note are the Kirby Report (2002) and the Romanow Report (2002). Kirby, in his report, focused on identifying Ottawa’s five key roles in health care: financing, research and evaluation, provision and monitoring health infrastructure, population health, and service delivery to specific groups (for example, the military and Indigenous people). Kirby also noted that the poor “health conditions of Aboriginal people on and off reserves was becoming more prominent” (Fierlbeck, 2011, p. 50).

Against the background of a debate about private for-profit service delivery versus the commitment to the public system in place, Romanow (2002) called for the creation of a Canadian Health Care Covenant. In the report, Building on Values: The Future of Health Care in Canada, Romanow suggested that this “new Canadian Health Covenant should be established as a common declaration of Canadians’ and their governments’ commitment to a universally accessible, publicly funded health care system” (p. 83). Romanow also proposed that additional funding should be targeted for home care, which could become the basis of a national home care strategy, and that the Canada Health Act should be revised to cover home mental health intervention, case management services, and post-acute home care and palliative home care. The Romanow Report set
the stage for the greater use and comprehensive management of electronic health records information and technology.

Following the reports by Kirby and Romanow, subsequent reports and activities were focused on the mental health care of Canadians (for example, Out of the Shadows, the 2006 report chaired by Kirby and Keon about mental health) (Fierlbeck, 2011). Unfortunately, few of the recommended directions for mental health services have been lasting (Villeneuve, 2017).

These multiple reports across Canada, and their uptake, were an indication that Canadian citizens have had an ongoing historical commitment to enhancing Canadian health care systems. Canadians have been, and continue to be, ready to be engaged in understanding, valuing, reviewing, promoting, and using health care. However, over time, the reality of rising health care costs has required governments to turn their attention to finding strategies to contain the escalation of expenditures.

**Federal-Provincial Funding**

The federal government raised concerns in 1977 about the rapidly escalating federal health care costs, and began to seek new and different ways to finance health care. Thus, they developed a system that same year “that permitted them to place clear and predictable limits on the amount of funding directed to the provinces” (Fierlbeck, 2011, p. 51). The proposed system included a cost-sharing arrangement between the federal and provincial governments for funding health care. This arrangement included a system of “block funding,” with a formula of 25% direct cash payments, plus tax points (13.5 + 1.0 tax points)4 transferred to the provinces (Van Loon, 1980, p. 349). These public funds were all to be offered under the same principles as HIDS and Medicare (i.e., public administration, comprehensiveness, universality, portability, and accessibility) (Fierlbeck, 2011 p. 21). This arrangement became known as the Established Program Financing Act (EPF) (1977). However, the outcomes of this block funding program still left wide room for deviations in practice in each province. These included deviations from the goal of a national health care system, some loss of control of health care standards, increased pressure for user fees,
and criticisms that the process favoured the richer provinces (Fierlbeck, 2011).

Monique Bégin’s appointment as the federal Minister of Health and Welfare in 1977 ensured that the federal government had a champion for its universal health care programs. Bégin, known as the “saviour of [M]edicare,” (Bégin, quoted in Hibler, n.d) wrote:

[B]y 1979, I concluded that extra-billing and user-fees were a cause of erosion of the system and that something had to be done. But what and how? The constitutional challenge — controlling provincial institutions and health professional behaviour — was not insignificant and was the most important task to address. It took almost three years to find a way and we succeeded thanks to top constitutional experts outside of government. Convincing Cabinet was also a challenge. (quoted in Fierlbeck, 2011, p. 20)

**The Canada Health Act**

Seen as the next logical step, the *Canada Health Act (CHA)* of 1985 replaced the *HIDS Act* and the *Medical Care Insurance Act*. Through its introduction, the federal government sought to correct the negative effects of block funding. In the preamble to the *CHA*, emphasis was placed upon the need for cooperative partnerships of governments and health professionals, as well as voluntary agencies. These criteria were stressed as critical to the health and well-being of Canadians. It was at this time that the additional principle of *accessibility* was added to the set of four principles which had been established and confirmed in Medicare. The intent of this addition was to ensure that all residents of a province or territory were entitled to health care based on uniform terms and conditions. The five principles of the *Canada Health Act*, as paraphrased from Villeneuve (2017, p. 86), are

- Public Administration: All provinces and territories must administer Medicare on a not-for-profit, single-payer basis.
- Comprehensiveness: The insurance program must cover all medically necessary services.
• Universality: Every resident of a province or territory must have access to public health insurance based on uniform terms.

• Portability: When a provincial or territorial resident requires access to insured services while temporarily outside their own province or territory, or outside of Canada, equivalent services to what they would receive in their home province must be provided.

• Accessibility: Canadian residents must have reasonable access to insured health services, free of charge or other restrictions, and must not be discriminated against because of, for example, age, income, or health.

Both provincial and federal governments have varying degrees of jurisdiction over different aspects of health care. However, it has generally been accepted that the provinces and territories have primary jurisdiction over the organization and delivery of health care (Romanow, 2002). To appreciate Canada’s funding approach, it is important to remember that although Canada’s fragmented health care system is coordinated by the federal government, the provinces and territories control the system and consent to these arrangements (Fierlbeck, 2011). Fierlbeck stated that it is only public opinion and cash that give a national structure to Canadian health care, and both variables are unpredictable.

Access to Health Care: The Citizen’s Health Care Card

To operationalize the provisions of the CHA, each Canadian citizen carries a unique provincial health care card, which gives them access to health care, for example, at an emergency department. Physicians’ office personnel and laboratories also use the card number to provide services to citizens without out-of-pocket payment. The prohibition placed upon this use is that extra-billing is not allowed. Most Canadians under the age of 60 take this card, and the access to health services it provides, for granted. They do not realize that prior to the mid-1960s, individuals had to pay out of pocket for each service in order to see a health care professional and receive health care, x-rays, and other medical tests. One of the authors of this chapter (Storch) experienced the inability to access
necessary health care when she was in the United States, as she
describes in the following personal narrative.

PERSONAL ETHICS NARRATIVE

A Challenge Accessing Urgent Health Care Services

In 1996, I was a Visiting Professor at the Kennedy Institute of Ethics and Georgetown University in Washington, DC. During my final month in Washington, I experienced a very sore throat that lasted several days, which I self-diagnosed to be a strep throat. I eventually had to seek care, and joined in the waiting line at a hospital outpatient department (OPD) nearby. The OPD was crowded with persons in need of care and their friends or relatives. I watched many being sent away from the department because they could not pay the price of examination nor the cost of the procedure and the necessary drug. For example, I watched two women appealing for help for their sick mother. They had no health insurance and were unable to pay, so they left with their mother untreated. When I reached the front of the line, I was told that I did not have any travel health insurance, and therefore, I could not be seen unless I paid several hundred dollars. Since my experience in the US, I have become more aware of the importance of protecting and sustaining a Canadian health care system that does not operate on the ability of the patient to pay for services.

Deficiencies in the Canadian Health Care System

Although significant progress had been made in almost all areas of health care by the time the CHA was passed in 1985, at least three areas of care did not experience sufficient progressive developments to meet the needs of Canadian residents. Those three areas were long-term care (LTC), mental health and illness care, and improved services for Indigenous people, all of which continue to be problematic. In what follows, we provide a brief overview of some of the deficiencies in these areas. Please refer to Chapters 15, 10, and 5 for more detailed discussions of long-term care, mental health, and Indigenous health care, respectively.
Deficiencies in Long-Term Care Services

Inadequate funding for long-term care in Canada was clearly recognizable during the COVID-19 pandemic (Estabrooks et al., 2020). Since nursing homes fell outside the CHA, the principles applicable to acute care settings did not apply to long-term care. As residents in need of long-term care were among the sickest and most likely to die during the pandemic, this built-in inadequacy was immediately visible. Nurses were among those who witnessed first-hand the poor planning and inadequate provision for this sector of care, and, as a consequence, the many deaths from COVID-19 that occurred in long-term care (Picard, 2021).

Residents in long-term care became the victims of inadequate services resulting from a chronic lack of funding to cover the costs of sufficient nurses and other health care providers, as well as equipment for mobility. In addition to the need for improved long-term care funding, Canadian journalist Picard (2021) described infrastructure deficiencies in long-term care, which he noted have been decades in the making. Picard framed the issue this way:

Canada’s provinces need to make judicious use of the wrecking ball. What needs to replace many of our large, decrepit institutions are smaller, more home-like facilities that are built to the needs of residents. For example, elders with dementia need to be able to wander safely, not just be confined to rooms; homes need to be equipped on the assumption that everyone could have mobility issues. (p. 168)

Picard (2021) identified other problems, including LTC sites being unprepared for the rapid spread of COVID-19, and the challenges created by the mix of residents’ needs. He also noted concerns about the inadequacy of resources, such as equipment and supplies, including PPE (personal protective equipment). In care homes with older infrastructure, isolation of those with COVID-19 was impossible because the structure of the buildings did not allow for isolation measures. The limitations of the structures also restricted, or seriously limited, family members from visiting loved
ones (even after visiting was permitted), thereby causing more grief and anguish for long-term care residents and their families.

**Deficiencies in Care of the Mentally Ill**

Fierlbeck (2011) provided a summary of mental health care in Canada, emphasizing that “mental care is not a subset of health care because it is qualitatively different from it” (pp. 196–97). Since mental health is under provincial and territorial jurisdiction, establishing asylums for those who were mentally ill slowed mental health reform for a long time in Canada. The federal government was not permitted to regulate policy in this area. Following the publication of the Romanow (2002) and Kirby (2002) reports, there was a call by some citizens for a return to the mid-sixties asylums, which were seen by some people as the best treatment for the mentally ill. However, in the Senate report *Out of the Shadows at Last*, the committee chaired by Kirby and Keon (Standing Senate Committee on Social Affairs, Science and Technology, 2006) called for a reinvigoration of Canada’s mental health care system. In 2009, a draft framework was developed for a comprehensive national strategy on mental illness and mental health. However, little action followed.

**Deficiencies in Health Care for Indigenous Peoples**

Deficiencies of health care for Indigenous peoples has not only been discussed in Canada, but was raised by the United Nations Commission on the Rights of Indigenous Peoples. Article 7 of the 46 Articles of the *United Nations Declaration on the Rights of Indigenous Peoples* (United Nations General Assembly, 2007) is focused on Indigenous individuals’ “rights to life, physical and mental integrity, liberty and security of person.” In 2008, Canada established the Truth and Reconciliation Commission of Canada (TRC) as part of the Indian Residential Schools Settlement Agreement (Government of Canada, n.d.). In 2015, the commission published their final report, which included calls to action to address child welfare, education, language and culture, health, justice, and all matters of reconciliation. Responsibilities for health in the *TRC Calls to Action* (2015) are reproduced below:
18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services. (pp. 2–3)

These commitments are critical to improving Indigenous health care in Canada.

**Other Deficiencies in Canada’s Health Care System**

Other gaps in Canada’s health care system that have always existed are the lack of coverage for dental care and prescription drugs. As the Liberal government’s federal budget was being prepared for presentation in April 2022, there was speculation that funds for both a dental care program and a Pharmacare program would be established. But on budget day, only one of these programs was introduced: a phasing-in of a dental-care program focusing on children (Department of Finance Canada, 2022a). In the Federal Budget 2022, the government stated that it would establish a Canada-wide Pharmacare bill by the end of 2023. The Canadian Drug Agency would be given the task of developing a list of essential medicines that would support implementation of this bill (Eckler, 2022). In considering the changes that are necessary in the
Canadian health care system, Lee et al. (2021) stated that “[r]eal change that fully embraces the values that Canadians want in their healthcare system will only come when there is broad public support for politicians to make difficult policy choices” (p. 40).

Proposed Solutions to Health Care Access: Privatization and Extra-Billing

With a clear choice by Canadians to value equality of access and maintain a strong publicly funded health care system, ways and means continue to be sought to improve funding of health services. Fierlbeck (2011) stated that “All health care systems are a mix of public and private elements; and many are structured on mechanisms (like social insurance schemes) that are neither fully public nor private” (p. 32). People advocating for private insurance, Fierlbeck noted, think it is more efficient and provides more choice.

Romanow (2002) created a clear distinction between necessary clinical and non-clinical services (for example, cosmetic surgery), proposing that only the latter could be provided on a for-profit basis. Yet, as Pauly (2004) noted, there has been an enduring belief among some that for-profit delivery of health services would be more efficient. Pauly stated that

it is essential that nurse leaders understand the way in which health care is funded and delivered in order to assess the ethical consequences of introducing particular health care reform strategies. The choice to support publicly funded health care and to refuse to allow further private for-profit health care in Canada is a value choice Canadians have made and can continue to make. These values are morally sound and consistent with nursing values and current research. (p. 199, emphasis in original)

In examining provincial practices with respect to private health care, Flood and Archibald (2001) reported that a significant private sector had not developed in any of the provinces up to 2001, and that measures had been developed to make adoption of the private sector less desirable. These authors attributed “the lack of a flourishing
private sector in Canada” to the rules prohibiting physicians from topping up their incomes by turning to the private sector (p. 830). However, by 2012, Forbes and Tsang suggested that there was a “privatization creep” underway in Canada, and they offered cautions toward preserving the public system. They suggested that the public system ultimately rests “on the will of the Canadian people” and indicated that “it would be a pity to see strong beliefs in equality buried by a lack of public preparation” (p. 4).

Questioning whether increased private health care for Canada would be the right solution, Lee et al. (2021) found that increases in private funding did not reduce health expenditures or improve health outcomes. These authors also recommended that ongoing debates about health care “should not be rooted in the source of funding but in the values Canadians regard as necessary for their health care system” (p. 31). In their study on the quality and sustainability of health care, Quinn and Manns (2021) did not find any evidence that resorting to private financing would impact challenges confronting Canadian health care. They urged that structures be found to “foster sustained physician engagement [which] will be critical in order to successfully improve the quality and sustainability of the healthcare system” (p. 9). Yet, in Canada, there continues to be ongoing and heightened discussion about privatization in health care as a potential way to better manage costs (Lee et al., 2021).

As an example of this ongoing discussion about privatization in health care, in Quebec, physicians warned the government and the public that family physicians were leaving the public sector for the private sector (Sherwin, 2022). Sherwin explained that the intentions of those leaving appeared to be a reaction to the Health Ministry’s attempt to legislate how primary care was delivered. Sherwin, along with other spokespersons, noted that “this was a bad move for the population” (p. 4). In addition, Sherwin indicated that some students in family medicine were seeking opportunities outside Quebec, and that several physicians were opening private clinics. Those monitoring this creep of family physicians leaving public clinics noted that Quebec was already short 1,000 family physicians.

Over 10 years ago, Fierlbeck (2011) stated that those critical of privatization “argue that attempts to push health care into the private
sector, if successful, would favour the wealthy while creating a disadvantage for the poor and ill” (p. 37). Doing so, these critics of privatization argued, would undermine the public system. Others agree that privatization should be resisted and instead, there should be enhancement of the public system to cover some additional private services not currently covered (CMA Duong, 2022; Yeo et al., 2020).

As another way of handling health care costs, there has been a growing tendency of health care providers to extra-bill and/or to impose user-fees on Canadians (Flood & Archibald, 2001). This is being done even though the \textit{CHA} bans extra-billing (sometimes called balanced billing by physicians). Extra-billing is a system whereby a physician charges their patients an additional fee or “extra charge” for services covered by the public plan (Flood & Archibald). This practice means that not only do physicians receive payment from the public plan, but they also receive whatever costs they bill patients. This was a practice Monique Bégin bemoaned in 1979, believing that it constituted an erosion of the health care system.

Extra-billing has been used in some provinces as a way to help cover health care costs. Shortly after the use of extra-billing began, HCPs and extra-billing program administrators were required to provide the federal Minister of Health with estimates of the expected costs incurred from extra-billing (or user fees), as well as the methods used to determine that amount. Although extra billing seemed to be widespread, locating those physicians who were extra-billing for health services eventually focused on only a few. One of these physicians was Dr. Brian Day of Vancouver, BC. In advertising his long-standing private specialist referral clinic, the Cambie Surgery Centre, Day continued to challenge federal and provincial governments about the right to operate and directly bill those who used the clinic’s services. Day’s claims were focused on long wait times in the public system. He believed this should be addressed by allowing physicians, who worked within Medicare, to also be allowed to sell their services to people willing to pay for faster care. However, as mentioned previously, under the \textit{CHA}, physicians are prohibited from providing for-profit care. In his argument against this prohibition, Day took his challenge to various BC courts where he lost his case a number of times (Baron, 2021; Canadian Doctors for Medicare (n.d.); CBC News, 2020; Fine,
Some consider this a huge win for public health care; however, Day continued his challenge by seeking approval from the Supreme Court of Canada to hear his case (Flood & Thomas, 2021). In April 2023, the Supreme Court dismissed Day’s appeal and the case will not be heard by the court (CBC News, 2023). Nonetheless, it is clear that the discussion about privatization of health care in Canada will be part of future debates about health care system reform.

**Moving Toward Change in Health Care**

There are changes being proposed to improve health care in a variety of areas (Wherry, 2022). For example, in early 2022, a draft of national long-term care services standards was released for public review (CSA Group, 2022). In the draft, the Standards Council of Canada focused on six foundational principles to inform the development of the national standard:

1. Homes in LTC are both workplaces and homes.
2. Homes are focused on the perspectives of LTC residents.
3. Resident-centred care focuses on equity, cultural safety, inclusion, diversity, and attention to systemic racism.
4. Residents in LTC have a right to live at risk.
5. Improving resident-centred care requires continuous data collection.
6. Meeting LTC standards requires mechanisms to enable achievement.

Ethics in Practice 3-1, below, exemplifies the hope that APNS and others have to improve the long-term care system.
Moving Forward on Reconciliation with Indigenous People

The federal government continues to work with Indigenous people to improve housing, to support children and education, and to respond to the Truth and Reconciliation Commission’s Calls to Action (Department of Finance, 2022b). Among the successes include the lifting of 131 long-term drinking water advisories by March 21, 2022. Also, since 2016, the government committed nearly $4 billion toward meeting the needs of First Nations children through a program called Jordan’s Principle.6

Although progress has been made, widespread deficiencies in Indigenous communities remain to be addressed, as articulated in

ETHICS IN PRACTICE 3-1

A Valiant Agent of Change

Rhys is a nurse practitioner who works in long-term care. He changed his workplace in the last eight months, transitioning from working in a critical care unit to working in a nursing home. Rhys made this move because he wanted to respond to the difficult situations in nursing homes that came to light during the COVID-19 pandemic. He has become very aware of the shortage of staff in long-term care and is appalled at the conditions under which many of his nurse and care aide colleagues work. Nurses and care aides working alongside Rhys tell him that “he will get used to it; that is just how long-term care is run.” He does not accept that for an answer and he is seeking a way to change this reality. He comes to you, an advanced practice nurse and nurse leader, seeking advice on actions he might take to better understand the situation and to make needed changes.

REFLECTIVE QUESTIONS

1. What steps would you suggest Rhys take to collaborate with other nurse practitioners active in long-term care to initiate change?

2. How could Rhys work with leaders in his organization to initiate progressive change in his long-term care facility?

3. How might Rhys include residents and their families in planning for change?

4. How might Rhys ensure that all involved are acquainted with the draft national long-term care services standard?
the *Truth and Reconciliation Commission of Canada: Calls to Action* (2015). Advanced practice nurse leaders have a role to play in attending to the calls to action. The following Ethics in Practice scenario focuses on improvements needed in health care in Indigenous communities, as discussed in the *Truth and Reconciliation Calls for Action*.

**ETHICS IN PRACTICE 3-2**

*Developing a Plan for Improved Primary Care*

Kelly is an advanced practice nurse who has been appointed to co-lead a new committee designed to plan for changes in primary care in a First Nations community. Kelly was born in the community and identifies as having Coast Salish ancestry. The committee’s mandate is to develop a plan that will address the deficiencies in access to primary care in their community. Kelly is employed by the First Nations community and has permission to invite people to join the committee from the community. She may also invite professional advisors and service providers whom she believes could make a significant difference to the community’s planning.

**REFLECTIVE QUESTIONS**

1. What should Kelly consider in regard to criteria, membership, and process when establishing the committee?

2. What kinds of preparation and support are needed to create an effective committee?

3. What are some ideas about how communication can be set up to keep the community informed?

4. How might Kelly build constructive dialogue and trust among/between diverse stakeholder members on the committee and within the broader community?

**Nursing Leadership: Political Action of the Canadian Nurses Association**

Given the challenges within the health care system, and the need for progressive change, sustained and skilled leadership by nurses across Canada is essential. This leadership is being demonstrated by the Canadian Nurses Association, as they have been collaborating
with other national professional bodies in political action to influence policy and practice changes required for health system reform. In a joint paper with the Canadian Medical Association (CMA, 2013), the CNA provided evidence of the Canadian public’s strong support for the five principles of the *CHA*. At that time, they also urged that beyond hospital and physician services, prescription drugs, home care, and physiotherapy services should be included in plans for subsidized care.

In March 2020, the CNA prepared a new paper on intraprofessional collaboration, which urged regulated nurses to seek out and value each other and to recognize “the important contributions that each nursing designation makes to patient care and the health system” (CNA, 2020a, p. 1). Included in the paper was a focus on resources required to promote and support optimal intraprofessional collaboration. The CNA next developed a brief on how long-term care could be improved; this was delivered to the Government of Canada in May 2020 (CNA, 2020b). The writers of the brief asked the federal government to appoint a committee of inquiry on aging. Further, they urged the federal government to work with provincial, territorial, and Indigenous governments, as well as public leaders, to conduct an evaluation on Canada’s response to COVID-19, and to encourage all levels of government to increase investments in “community, home and residential care to meet the needs of our aging population” (p. 2).

On June 1, 2020, a letter was sent by the CNA and the CMA to the Minister of Health, Health Canada and the Minister of Seniors, urging their attention to the challenging effects COVID-19 has had on the health care system, particularly LTC (CMA, 2020a). In December 2020, the Canadian Nurses Association joined the Canadian Medical Association and the Canadian Society for Long-term Care Medicine in an appeal to the federal government for national long-term care standards (CMA, 2020b).

On February 1, 2022, the federal government reinstated the position of the federal Chief Nursing Officer (CNO) for Canada. This action was preceded by years of lobbying by the Canadian Nurses Association. Due to a health workforce crisis, the re-establishment of the CNO role was welcomed as a significant step for nurses, and particularly for Canada’s health care system (CNA, 2022).
duction of this role has the potential to provide nursing leadership, and a nursing voice, for health system planning at the federal level. This is particularly important since, as the pandemic progressed, the loss of nurses and other health care workers was substantial and was emphasized in a news release from the CNA (2021) titled “Without health workers, there is no health care: Health care leaders call for urgent action at an emergency COVID-19 summit” (CNA, 2021). At the summit, the CNA and the CMA brought together approximately 40 national and provincial health organizations to develop short- and long-term actions for an effective COVID-19 response and to ensure that Canada’s health system remained sustainable.

**Improving Canada’s Health Care:**
**The Role of Advanced Practice Nurses**

Despite gradual improvements in the areas of deficiency noted in this chapter, two immediate problems for Canadian citizens are increasingly evident: (a) the lack of primary care providers (Xiao, 2022), and (b) the lack of timely access to health care services (Lee et al., 2021). There is an urgent need to address these two shortfalls, and advanced practice nurses (APNs) can play a significant role in meeting the health care needs of people in a variety of settings.

Nurses’ current level of preparation and certification for this role has extended their involvement in all fields of advanced nursing practice. As a result of the shortage of physicians, nurse practitioners (NPs) are considered by many to be able to bridge the gap in primary care. Bramham (2022) emphasized the lack of family physicians and promoted health reform; however, she overlooked the significant roles NPs could fill in health reform.

APNs are nurses who undertake graduate nursing education for advanced practice. They have studied specialized nursing and health care knowledge, gained substantial experience in clinical nursing, and engage in complex decision-making to serve health needs of persons, families, special groups, communities, and populations. It is imperative that APNs fill current and widening gaps in health care and provide more comprehensive care for all. APNs have a role in urban and rural centers and have major roles in meeting the needs of underserved populations.
In the past, nurses have served in the Northwest Territories, the Yukon, Newfoundland and Labrador, as well as in the northern areas of the prairie provinces. Although their preparation varied at that time, almost all grew into the role needed for what was often called “outpost nursing.” Outpost nursing was, and continues to be, an area of practice for registered nurses with experience, skills, and willingness to work in very challenging conditions, often in small, remote communities. Once again, it is time for nurses “who integrate graduate nursing educational preparation with in-depth, specialized clinical nursing knowledge and expertise in complex decision making to meet the health needs of individuals, families, groups, communities, and populations” (CNA, 2019, p. 13). These nurses are required now, more than ever. For example, with the growing shortage of physicians in primary care, it is timely for nurse practitioners to apply their knowledge and skills toward family practice to fill the void in primary health care. NPs who are working within primary health care are essential in filling the gap for those who are seeking a primary care provider (Whittaker, 2022).

**Conclusion**

In this chapter, we provided a brief history of how Canada’s health care system was built, including a focus on federal, provincial, and territorial responsibilities. We discussed federal legislative decisions and their effects on federal, provincial, and territorial obligations. Further, we described the challenges of the distribution of power in Canadian health care. The five principles of the *Canada Health Act* were discussed, with shortfalls in various health services identified. Current inadequacies in three areas of health care (deficiencies in long-term care, deficiencies in care of the mentally ill, and deficiencies in health care for Indigenous people) were identified. We argued that nursing leadership is essential in health care reform and that advanced practice nurse leaders have a role in addressing the deficiencies in health care, as well as other challenges noted in this chapter. Serious health care concerns, including the impact of the COVID-19 pandemic on the Canadian health care system, are expected to continue to challenge APNs, other HCPs, and the public in general. The knowledge and skills of advanced practice
nurse leaders are required in order to promote and provide quality health care for Canadians.

**QUESTIONS FOR REFLECTION**

1. *Are Canadian values about health care shifting, and, if so, what is responsible for this shift?*

2. *What are the ethical tensions associated with greater private for-profit health care funding and delivery in Canada for advanced practice nurse leaders?*

3. *What are the ethical responsibilities of advanced practice nurse leaders in response to tensions at the various levels of health care (micro, meso, and macro)?*

4. *What constraints or facilitators might advanced practice nurse leaders experience in taking action consistent with their ethical duties and obligations in the development of health care policy?*

5. *How has the history of the evolution of the Canadian health care system contributed to the current health care challenges we face?*
Endnotes


2 It is interesting to note that one of the authors of this book (Storch) was a recipient of one of these grants, which aided her in completing her Bachelor of Science in Nursing degree.

3 Douglas's passionate pleas for “free” health care earned him the title of “Father of Medicare” (Canadian Health Coalition, n.d.).

4 A tax point is a permanent transfer of income tax room from the federal government to provincial governments. The federal government reduces its basic tax rate by a specific percentage and the provinces increase theirs by an equivalent amount, thereby leaving total federal and provincial tax unaffected.

5 Extra-billing is a longstanding concern in Canada. See Flood and Thomas (2020).

6 Jordan’s Principle represents the government’s commitment to eliminate systemic barriers that prevent First Nations children from accessing the services and supports they need. Jordan’s Principle is named in memory of Jordan River Anderson, a young boy from Norway House Cree Nation in Manitoba. Jordan was born in 1999 with multiple disabilities, and stayed in hospital from birth since the federal and provincial governments could not agree on who would pay for home-based care. Jordan remained in hospital until he passed away at age five. In his memory, the House of Commons created Jordan’s Principle as a commitment to First Nations children to ensure they receive the services and supports they need (Department of Finance Canada, 2022b).

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Chapter 3: Health Care in Canada


PUBLIC HEALTH (PH) ETHICS is a relatively new but growing field of applied ethics (Bayer et al., 2007; Baylis et al., 2008; Dawson & Verweij, 2007; Lee, 2017). PH professionals have long grappled with ethical issues in their practice. It is only in the last 25 years that PH ethics frameworks—grounded explicitly in PH principles and values to address ethical issues in practice—have become available. Historically, public health nurses have not received guidance about their unique ethical concerns when relying on perspectives from health care ethics or nursing ethics. Instead, a rights-based
approach (Zahner, 2000), or the health care ethics principles of autonomy, beneficence, non-maleficence, and justice—specifically distributive justice (Beauchamp & Childress, 1979)—were used as the appropriate framework to support ethical PH nursing practice (Vollman et al., 2003). These approaches tend to be more relevant to clinical nursing practice than to PH nursing.

As PH ethics developed, theorists and practitioners across disciplines began to recognize that health care ethics did not provide an adequate theoretical foundation for PH ethics (Jennings, 2003). In the 1970s and 1980s, some authors proposed the need for a system of ethics specifically oriented to PH (Beauchamp, 1976; Lappe, 1986). Still, we have only claimed and named PH ethics as a distinct area of scholarship since the late 1990s (Kass, 2004). In fact, according to Kass, authors rarely used the term “public health ethics” prior to the year 2000. To illustrate the growth in the field, I conducted a Google Scholar search for the term “public health ethics,” covering the 30-year period between 1980 and the end of 2009. This search produced 2,360 references, for an average of 30 publications per year. A similar search in Google Scholar—for the next 12 years—a period spanning from the beginning of 2010 to the end of November 2021—returned a list of 9,560 references on the same search term, “public health ethics,” for an average of 869 per year. Although Google Scholar is not likely to have captured all publications on the topic, it does give a good sense of the significant growth of scholarly literature in the field.

Recent developments in nursing ethics, as influenced by feminist and relational ethics, have broadened the ethical focus in the field to encompass at least some of the ethical concerns of PH nurses. Yet, there are almost no PH nursing-specific ethics frameworks available. Considering that PH nurses focus primarily on communities and populations—as does PH in general—it is likely that ethical issues in PH nursing will be best addressed by emerging developments on relational frameworks, although these frameworks may need to be modified for use in PH nursing. I will discuss this further in the section on PH nursing ethics.

In this chapter, I build on my analysis of PH ethics in the 2013 (second) edition of Toward a Moral Horizon: Nursing Ethics for Leadership and Practice (Storch et al.) and add new developments in
PH ethics since 2010. I review the development of PH ethics through two historical streams, define the term PH and its core functions, the meaning of the term “public” in relation to PH, and describe the history and evolution of the field of PH ethics. I discuss how PH ethics differs from health care ethics, and how it has been implemented in nursing. A range of current PH ethics issues are presented, including a discussion of PH research ethics, environmental and global health ethics, and the ethics of pandemics. I conclude with a summary of key developments in PH ethics, and a listing of PH issues for the future. Finally, I pose some questions for reflection for readers.

What Is Public Health?

As Verweij and Dawson summarize in brief: “Public health is a contested concept” (2007, p. 13). It is a term with multiple shades of meaning that is often misunderstood. Some understand PH to mean health care provided within the publicly funded health system. This misinterpretation occurs, in part, because PH operates under the radar; people are generally unaware of its existence until a PH crisis strikes. Other aspects of the Canadian health care system, however, such as acute hospital care, are highly visible in the lives and awareness of Canadians.

The focus and scope of PH action is one aspect of PH that is increasingly contested. Some argue that PH should be narrowly conceived, dealing only with PH issues that relate directly and specifically to health matters, such as communicable diseases, clean drinking water, food safety, and the like (Bernstein & Randall, 2020). These issues, and how governments handle them, are generally uncontested and usually implemented without controversy. PH issues that have political dimensions, however, are often controversial. For example, proponents of a narrow scope for PH argue that addressing issues related to the environment, personal behaviour, and many of the determinants of health (e.g., education, income, employment) is beyond the scope of PH (Bernstein & Randall, 2020; Rothstein, 2002).

Potvin (2014) reported on articles from the Quebec press that proposed placing limits on PH and its scope. These writers argued
that (a) PH should stick to infectious diseases and not address social and economic policy issues; (b) PH should not be allowed to use its moral authority in areas not directly related to health; and (c) PH should not stray into areas of social action. Rothstein (2002) argued that just because social problems exist, that does not make them PH issues. He further argued that an all-inclusive notion of PH is ineffective and counterproductive, and suggested that the government overreaches when it engages in non-health-related actions, because such actions are not within the purview of PH.

On the other hand, many others, including most PH leaders and practitioners, support a broader model of PH that focuses on health inequities, social epidemiology, and the nature of causation in PH (Bernstein & Randall, 2020; Goldberg, 2008; Lurie & Fremont, 2009). Rather than focusing strictly on communicable diseases, they maintain that PH should be addressing the social, economic, and ecological determinants of health from a social justice perspective. Goldberg (2009), for example, suggested that if PH does not address the underlying causes of ill health and disease, PH practitioners are not doing their jobs and will not improve population health. Moreover, a broad scope is consistent with most widely accepted definitions of PH. Indeed, core competencies of PH (e.g., Public Health Agency of Canada, 2008) and codes of ethics in PH (e.g., American Public Health Association [APHA], 2019) explicitly define a broad scope for PH practice. Additionally, the history of PH in Canada demonstrates an increasing expansion of the scope of PH over the past century (Tam, 2021). Those who argue for a narrow scope of PH seem not to understand either the nature of PH or its development, aims, benefits, and history.

**Definition of Public Health**

Public health holds many meanings for many people. Here, I include one representative definition that will be useful for framing this chapter: Public health is “what we, as a society, do collectively to assure the conditions in which people can be healthy” (Institute of Medicine [IOM], 1988, p.1). Common elements across all definitions of PH include collective effort, societal responsibility, and attention to social and environmental health determinants. The moral aims of
PH are to promote health equity and to promote the health of the population as a social good that allows people to pursue other valued goals (Powers & Faden, 2006). As evidence accumulates about growing global health inequities, a concern with inequitable health status among disadvantaged and marginalized populations has emerged in PH (World Health Organization [WHO], 2008).

Since PH practitioners aim to improve the health of whole communities and the population at large, their strategies do not focus solely on individuals. With the guidance of PH professionals, local governing bodies (such as state/provincial governments, municipalities, or regional health authorities) provide societally oriented interventions. Providing safe water, ensuring a safe and accessible food supply, public sanitation, taking action to control or prevent communicable diseases, preventing chronic diseases, and promoting health equity are just some of the PH interventions that require collective rather than individual action. The collective nature of these activities often requires legislative authority and may infringe on the rights of individuals, thus raising distinctive ethical challenges. A range of public organizations such as non-profits, schools, professional groups, and others may also develop and deliver community-oriented interventions (Childress & Gaare Bernheim, 2015; Institute of Medicine, 2002).

**Core Functions of Public Health**

PH in most countries has a set of core functions. Not every country defines the core functions of PH in the same way. In the US, for example, there are three core PH functions: assessment, policy development, and assurance. In addition, the Centers for Disease Control and Prevention (CDC) (2020) in the United States has also identified ten essential services of public health, developed originally in 1994 and updated in 2020, to bring PH in line with current and future PH practice.

In Canada, we define the core functions of PH on a federal level as health promotion, health surveillance, disease and injury prevention, population health assessment, and emergency preparedness and response (Canadian Institutes of Health Research, 2021). Provinces have developed their own frameworks to
further define core PH functions in their region. For example, in British Columbia (BC), the Ministry of Health developed a framework for PH in 2005. This framework included a broad overview of PH (reflecting an expansive model), the core functions and programs of PH, and strategies in PH. It provided an equity and population lens that shapes the understanding of PH and its functions, as well as the capacity of systems to support PH activity (e.g., health information systems, human resources, research, legislation, and others; BC Ministry of Health, 2005). Twelve years later, the provincial government updated the core functions framework as the Guiding Framework for PH (BC Ministry of Health, 2017).

Defining the “Public” in Public Health

There are several ways that “the public” is understood in PH. Because we cannot give a solid, all-encompassing definition for the term, we will instead explore the various ways in which the notion of the public is contextualized in discussions around PH.3

We can understand the term “the public” as a collection of people, as a space for action, or as a set of values (Mold et al., 2019). People often use the term “public” synonymously with “population,” a term that has long been “bound up with the history and practices of PH” (Mold et al., p. 10). As Krieger (2012) proposed, a population is more than a statistical entity; rather, we must understand the term “population” with respect to its internal relationships and its connections to other populations. Thus, a population is inherently relational. As we shall see, these ideas about the meaning of “public” and the relational nature of populations undergird some perspectives in both PH and feminist ethics.

The public and PH are not fixed and concrete entities. Rather, they are social constructions that “change and vary by time and place” (Mold et al., 2019, p. 7). Because of its broad focus, PH tends to encompass a range of publics; the meaning of the term “public” itself is slippery. As claimed by Verweij and Dawson (2007), the public is both a target of action and a process of collective action. “As Newman and Clarke argue, part of what makes the public is a set of legal and democratic values that mark out a domain distinct from private interests” (Mold et al., 2019, p. 9, paraphrasing Newman &
In a recent review of the distinctive challenges of PH ethics, Faden et al. (2019) defined the object of focus in PH as a community, the public, or a population, with each term carrying subtle differences in meaning. Community is the “most morally laden” of the three terms (p. 5). It refers to a cohesive group that shares values, language, culture, and history. Community’s etymological similarities with “common” reflect community’s appeal to the common good. Unlike community and common, the public is also “a discrete unit that corresponds with state boundaries” (p. 4) and thus connotes an official political structure. The term “population” tends to minimize the implication of shared characteristics and has a less “inward looking orientation” (p. 5) than the term “community.”

**What Is Public Health Ethics?**

In a broad sense, the purpose of using PH ethics is to guide practical, ethical decisions about problems that affect population or community health. Scientific evidence informs ethical analysis, and PH leaders make decisions in accordance with accepted values and standards (Ortmann et al., 2016, p. 3). PH ethics builds on its parent disciplines of PH and health care ethics. It is “a systematic process to clarify, prioritize, and justify possible courses of PH action based on ethical principles, values and beliefs of stakeholders, and scientific and other information” (Centers for Disease Control, 2017, “Public Health Ethics”, para. 1). Often, practitioners use an ethics framework to operationalize and guide the process of ethical analysis.

Gostin (2001) proposed three analytic perspectives on PH ethics: the ethics of PH, ethics in PH, and ethics for PH. Callaghan and Jennings (2002) added a fourth type they name “critical public health ethics” (Nixon et al., 2005; Nixon, 2006).

An important take-away message from the early years is that there is broad agreement that the principles of health care ethics (autonomy, beneficence, non-maleficence, and justice) are not always a good fit for the ethical issues that arise in PH (Kass, 2001; Keeling & Bellefleur, 2016; Nuffield Council on Bioethics, 2007; Turaldo, 2009). This is because the principles have an
individualistic orientation centred on client rights; priorities which sometimes work to the exclusion of the common good.

The most common ethical theories applied in the early days of PH ethics derived from various strands of liberalism that many authors argued do not provide an adequate moral foundation for PH (Callaghan, 2003; Ortmann et al., 2016). Several authors have since attempted to lay out a set of principles more relevant to the moral aims of PH (Baylis et al., 2008; Upshur, 2002), but even these were limited. Recently, authors have specified a broader range of principles appropriate for PH (e.g., Filiatrault et al., 2017). In a systematic review, Abbasi et al. (2018) concluded that there has been a shift in PH ethics frameworks from liberal and individualistic values towards an emphasis on the collective values and principles of community.

Although there is a strong orientation to social justice and equity in PH and its ethics (Powers & Faden, 2006), many writers still see PH primarily from a distributive justice perspective (the fair allocation of resources) (e.g., Childress & Bernheim, 2015; Persad, 2019). Ethics for PH, however, reflects a populist ethic which Gostin (2001) argued is intended to serve the interests of populations, but in particular, the needs and interests of the marginalized and disadvantaged. A populist approach thus reflects an appeal to the common people. Such an ethic needs to account for more than distributive concerns (Moroni, 2020).

The strong connection between social justice and critical PH ethics is also worth noting. To date, there have been few publications on critical PH ethics. Even the journal *Critical Public Health* lists only seven articles under the search term “critical public health ethics.” Although there has been some discussion in online blogs about the relationship between critical PH ethics and the critical sociology of public health (Lupton, 2012), that discussion has not been developed further and is now somewhat dated. I suggest that more work to develop the field of critical PH ethics might expand the theoretical base of PH ethics in a fruitful direction.

Among other factors, “institutional arrangements and prevailing structures of cultural attitudes and social power” (Callaghan & Jennings, 2002, p. 172) influence the development of PH problems and related ethical issues. Callaghan and Jennings call for policies
and interventions to be “genuinely public or civic endeavors” and suggest the need for “meaningful participation, open deliberation, and civic problem solving and capacity building” (p. 172) in the creation of both the interventions and the management of ethical issues that come with them. This commitment to participation is a long-standing tradition in PH and health promotion (Francés & La Parra-Casado, 2019; MacDonald & Mullet, 2009). It is also consistent with a range of philosophical perspectives, including feminist perspectives, communitarian perspectives, and perspectives encouraging deliberative democracy (that is, a democracy in which deliberation is seen as a crucial aspect of decision making). Reflecting these ideals, public participation is included as a value or principle in some newer PH ethics frameworks (e.g., Abbasi et al., 2017; Marckmann et al., 2015).4

**How Does Public Health Ethics Differ From Health Care Ethics?**

The difference between health care ethics and PH ethics lies in the distinction between PH and health care. In health care ethics, the main focus is on the needs, interests, and concerns of individual patients as they interact with and receive care from practitioners and the health care system for their illnesses. In PH ethics, however, practitioners focus on the health of the population as it is affected by social and political structures as well as environmental conditions.

A more extensive discussion of the difference between health care ethics and PH ethics can be found in MacDonald (2014), where I discussed three main features of PH that create specific moral concerns. First, the initiative in PH versus health care comes from the professional, not the patient. Second, since PH interventions target populations or communities specifically, the benefits for the individual may be negligible (i.e., the classic “prevention paradox”; Raza et al., 2018).5 Third, PH interventions are potentially pervasive (e.g., water fluoridation), such that it is difficult for individuals to either refuse or consent to participation. These distinct foci in PH versus health care create very different demands for ethical analyses, and each raises its own unique ethical challenges regarding choice, individual good, and the common good.
Another difference between health care ethics and PH ethics is that some health care ethicists have not typically demonstrated a concern with the social determinants of health (Baylis et al., 2008; Pauly, 2008), although this has begun to change (Puyol, 2012; Spruce, 2019). For example, Levin and Fleishman (2002) observed that PH ethics has much to contribute to bioethics “by broadening the primary focus of bioethics from individual autonomy and clinical care to include the contextual issues in health care decision making, the value conflicts inherent in population-based programs, and the social and structural determinants of population health” (p. 166). Twenty years ago, Callaghan and Jennings (2002) emphasized that the time had come to integrate the ethical problems of PH into bioethics.

Some authors, especially during the COVID-19 pandemic, called on health care ethicists to draw on the insights and developments of PH ethics (Saenz, 2021). Dunham et al. (2020) suggested that because COVID-19 has introduced such significant challenges for clinicians and health care systems everywhere, practitioners who care for individual patients also need to consider and orient themselves to the common good. That is, clinicians need to understand the collective public as their patient and learn about collective ethics. Dunham et al. argued that those who understand collective ethics will be better able to understand system-based decisions. This will be necessary to minimize moral distress for health care practitioners, because a shift to prioritizing the collective over the individual is likely to put many practitioners into a zone of discomfort where they believe that they are “practicing at the edge of [their] competency” (Dunham et al., 2020, p. 474). Organizational supports will therefore be necessary to facilitate this change.

DeBruin and Leidar (2020) added that in PH crises like the COVID-19 pandemic, which involve resource shortages, health care systems can become overwhelmed. In these cases, norms guiding care may have to shift from individual well-being and autonomy to focus on common benefit. That being said, efforts to strike a balance will be important because practitioners will still have to care for their individual patients.

In the early years, there was a deep divide between the commitments of theorists in health care ethics and commitments of those
working in PH ethics (Bayer & Fairchild, 2004). “The core values and practices of PH, which often entail the subordination of the individual for the common good, seem to stand as a rebuke to the ideological impulses of bioethics” (p. 474). Thus, Bayer and Fairchild concluded that standards for guiding PH ethics cannot be derived from the assumptions of bioethics, in which individualism is dominant and the principle of autonomy has pride of place. As discussed above, and as we shall see later in the chapter, this perspective is beginning to shift.

Implementing Public Health Ethics in PH Nursing

Despite growth in the fields of health care ethics and nursing ethics over the past decades, there has been little development in ethics specific to PH nursing. Few nurse researchers have conducted empirical studies on ethics in PH nursing. This is illustrated in a recent systematic review of reviews on bioethics topics (Mertz et al., 2020). The authors found that of the 76 reviews included in the study, most were from the fields of nursing and medicine. Fifty percent dealt with clinical ethics, 36% with research ethics, but only 14% with PH ethics.

Aroskar (1979, 1989), Fry (1983, 1985), and later, Oberle and Tenove (2000), identified that the moral concerns of PHNs might not be the same as those of most other nurses. These nursing studies predated recognition by most bioethicists that ethical issues in PH differed from those in health care more generally. The authors of the nursing studies suggested that the professional codes of ethics in nursing might require PHNs to violate those codes while engaging in population-focused nursing practice.

Despite these early observations by PH nursing authors, in a review of the ethics content of community health nursing textbooks, Zahner (2000) found that many had no ethics content at all, and only 30% had separate chapters on ethics. When ethics was included, the dominant ethical theory was a duty-based, deontological perspective. Surprisingly, given its prominence in PH more broadly, Zahner found a utilitarian perspective in only 14% of the sample, while human rights and distributive justice theories
(versus social justice) were the theoretical basis in 23% and 25% of the texts, respectively. None of the authors of these texts mentioned a communitarian ethical perspective, nor did they discuss the distinction between PH and health care ethics. This is consistent with Kass’s (2004) observation that very little appeared in the literature on PH ethics prior to the year 2000.

In summary, few nursing articles relevant to PH ethics appeared in earlier stages of PH ethics history. Despite the fact that the PH ethics literature in nursing was scant early in the history of PH ethics, the nursing authors cited above were actually ahead of the field in identifying ethical issues in PH practice, and particularly in observing the frequent tension between individual autonomy and the collective good.

The following definition of a PH nurse provides important clues about the ethical challenges for PHNs. “A PHN/community health nurse combines knowledge from public health science, primary health care (including the determinants of health), nursing sciences and the social sciences. The PHN focusses on promoting, protecting and preserving the health of populations” (CPHA, 2010, p. 8). Although the focus is on population health, PHNs do some of their population-focused work with individuals. PHNs also recognize that individuals and communities are inextricably linked (Diekemper et al., 1999); thus, PHNs must take a relational perspective. This dual nature of the PHN role, with a concurrent focus on the care of individuals and the health of the population, creates unique ethical challenges for PHNs (Oberle & Tenove, 2000) that are not generally experienced by nurses working in other areas of practice nor by other types of PH professionals.

Given the lack of PH nursing ethics frameworks, professional codes of ethics for nurses are important guides for practice because they reflect a professional consensus on matters of ethics. As noted earlier, the authors of one systematic review found that the majority of ethical frameworks used in nursing were the codes of ethics for professional nursing organizations (Mallari & Tariman, 2017). In the past, however, several authors pointed out that nursing codes of ethics did not reflect the nature of PHN practice, nor did they provide guidance for the unique ethical issues in PH nursing (Folmar et al. 1997; Fry 1983, 1985). The 2008 and 2017 versions of
the Canadian Nurses Association (CNA) *Code of Ethics for Registered Nurses* both address some of the concerns of PHNs. The language used in these documents opens the possibility that ethical decisions might be different when the community or population is the primary concern. This is particularly evident in the values listed in the 2017 CNA *Code of Ethics* under the headings of “Promoting Health and Well-being” and “Justice.” For example, in the third ethical responsibility under “Promoting Health and Well-Being,” the 2017 CNA *Code of Ethics* specifies that when a community health intervention interferes with individual rights, nurses advocate for and use the “least restrictive means.” This is one of the earliest PH principles identified in the first PH ethics frameworks (Kass, 2001; Upshur, 2002), and it addresses the individual versus collective tension in PH ethics. Thus, its inclusion in the 2017 version of the CNA *Code of Ethics* is an important improvement.

In addition to the value statements and their accompanying ethical responsibilities, the 2017 CNA *Code of Ethics* includes a set of ethical endeavours. These endeavors are broad aspects of social justice that relate to the need for social and system change to promote health equity. The CNA did not consider these endeavors to be part of nursing’s core ethical responsibilities, although they are still part of ethical practice. I would argue, however, that several of these ethical endeavours actually do reflect the core ethical responsibilities of PH nursing, even if they are not core responsibilities for the rest of nursing.

Several statements under the heading “Ethical Endeavours” in the 2017 CNA *Code of Ethics* are explicitly reflected in national community health nursing documents defining the roles, responsibilities, and competencies of PHNs (Community Health Nurses of Canada, 2019; Canadian Public Health Association, 2010b). These include

utilizing the principles of primary health care for the benefit of the public and persons receiving care …
recognizing the significance of social determinants of health and advocating for policies and programs to address them … maintaining an awareness of major health concerns, such as poverty, inadequate shelter, food
insecurity and violence, while working for social justice, individually and with others, and advocating for laws, policies and procedures that bring about equity. (p. 18)

Thus, the 2017 version of the CNA Code of Ethics represents a further step forward in reflecting the ethical responsibilities of PHNs. In the US, there is a code of ethics for PH (American Public Health Association, 2019) that PHNs are expected to follow in addition to their own nursing code of ethics. A similar PH code in Canada could support PHNs in fulfilling their ethical responsibilities for population and community health. The following Ethics in Practice case illustrates the unique ethical responsibilities of PHNs.

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**ETHICS IN PRACTICE 4-1**

**E-Cigarette Legislation**

The federal government has asked your health unit to comment on a new regulatory framework for electronic cigarettes in Canada, specifically the recommendation that “[E]lectronic cigarettes (e-cigarettes) that resemble conventional cigarettes (e.g., similar size, false filters, lighted tip, etc.) should be prohibited in Canada.” Given your PH nursing background in smoking prevention, and your involvement in the Canadian Student Tobacco, Alcohol, and Drugs Survey, your Medical Officer of Health has asked you to prepare the health unit’s response.

The intent of the legislation is to avoid “renormalizing” conventional cigarette use and prevent e-cigarettes from becoming a “gateway” for cigarette smoking, especially among youth. However, the proposal may also diminish the adoption and use of e-cigarettes by current smokers trying to quit. (Adapted from a case developed by the National Collaborating Centre for Healthy Public Policy ([2016])).

**REFLECTIVE QUESTIONS**

1. What are the ethical issues in this case?

2. What PH ethics principles and/or values are relevant to this situation?

3. How would you go about making this decision?

4. What decision would your health unit make and why?
The development of PH nursing ethics in Canada has lagged behind both PH ethics and nursing ethics. A feminist relational perspective on nursing ethics, however, has informed some areas of PH nursing practice such as tuberculosis (TB) care and treatment (Bender, 2009), working with high-priority families (Browne et al., 2010), child protection clients (Marcellus, 2004), and perinatal substance users (Marcellus, 2005), all of whom might be considered vulnerable, oppressed, disadvantaged, or marginalized in some way.

Drawing on notions of relational practice (Hartrick Doane & Varcoe, 2007), relational autonomy (Sherwin, 2004), and relational ethics in nursing (Bergum, 1994), the analysis of PH nursing practice with the population groups as described by the authors above reveals considerable congruence with other perspectives on PH ethics. Examples include a relational account of PH ethics (Baylis et al., 2008; Kenny & Sherwin, 2008; Kenny et al., 2010), critical PH ethics (Callaghan & Jennings, 2002; Nixon, 2006), feminist ethics in PH (Rogers, 2006), and a communitarian ethical perspective (Etzioni, 2003; Jennings, 2007; Selznick, 1998). These perspectives are also reflected in emerging PH ethics frameworks. The following Ethics in Practice case illustrates that “doing good” might not be as simple as it seems, because ethical challenges arise.

ETHICS IN PRACTICE 4-2

Ethical challenges with HIV Treatment as Prevention (TasP)

Recent scientific evidence has generated enthusiasm about a new approach to treating human immunodeficiency virus (HIV). Early access to HIV testing and immediate treatment for those who test positive—an approach referred to holistically as “treatment as prevention” (TasP)—is a powerful way to help end the HIV pandemic. Epidemiological and clinical researchers have demonstrated that the early treatment of HIV infection can have positive health outcomes not only for those treated, but also for preventing HIV transmission to non-infected people. Additionally, TasP can reduce TB morbidity and mortality.

You are a PHN and your Medical Health Officer and Chief Nursing Officer have asked you to work with a team to develop the TasP program. You recognize that to achieve the aims of TasP, several important ethical challenges must be addressed, including...
In conclusion, nursing ethics and PH ethics have common ground through their application of feminist relational ethics. Further advancements in the field will require drawing on the work above to develop ethical frameworks or guidelines for PHNs in dealing with other major ethical challenges in PH, such as the issues discussed below related to pandemic ethics.

What Is the History of Public Health Ethics?

The history and accomplishments of PH can be divided into three streams. The first stream reflects a history of coercive and authoritarian actions to control raging epidemics in the Middle Ages. Such measures persisted into the past two centuries, with severe restrictions not always imposed equitably across the population (Fairchild et al., 2020; Nixon et al., 2005). This history has haunted PH into the 20th century in relation to the epidemics and pandemics of Spanish flu, polio, Ebola and others. This history continues to haunt PH to this day in relation to other infectious disease pandemics such as Severe Acute Respiratory Syndrome (SARS-CoV), swine flu (H1N1), avian influenza (including H5N1 and H7N9), and COVID-19 (SARS-CoV-2).

According to Kass (2004), Stage I of the modern era of PH ethics began in the 1970s and 1980s with the ethics of health promotion and the PH response to Aquired Immune Deficiency Syndrome (AIDS) (MacDonald, 2014). This response was known as AIDS exceptionalism (Smith & Whiteside, 2010), defined as “departures...
from standard PH practice and prevention priorities in favour of alternative approaches to prevention that emphasize individual rights at the expense of public health protection” (Fisher et al., 2009, p. 45). This created its own set of ethical problems (MacDonald, 2014). Recently, Benton and Sangaramoorthy (2021) have revisited the question of whether AIDS exceptionalism has exacerbated the problems associated with exceptionalism in other areas of public health. They argue that it has, because this exceptionalism has further fragmented health delivery systems and reproduced unintended inequalities. They suggest that to end the AIDS pandemic, we must also end AIDS exceptionalism and return to tried and true principles of PH action.

The second historical stream reflects a more positive history of social justice and political action to improve population health (Nixon et al., 2005). In this stream, nurses were engaged in many progressive social movements (Beauchamp, 1976; Buhler-Wilkerson, 1993). During this period, PH achieved major advances such as improved water quality and sanitation, sewage treatment, maternal and child health services, improved housing and working conditions (Lalonde, 1974; Rutty & Sullivan, 2010), and the control of several communicable diseases.

The result of these and other PH measures was a dramatic improvement in population health, with increased life expectancy and reduced morbidity in both Canada and the US. In fact, PH interventions, rather than medical treatment and health care, contributed substantially to these improvements (Rutty & Sullivan, 2010; Tam, 2021). In Canada, there was a 30-year gain in life expectancy over the course of the 20th century, 25 years of which was due to PH interventions (Canadian Public Health Association [CPHA], 2010a; Tam, 2021). In the US, life expectancy increased 3.3 years between 1990 and 2015; 44% of the improvement was due to PH measures (Buxbaum et al., 2020).

In Stage II (from the beginning of the 21st century until about 2010), frameworks specific to PH ethics began to be developed. At this time, ethicists proposed new philosophical and political foundations that went beyond the classical utilitarian and contractarian theories (e.g., civic republicanism and communitarianism). It was in Stage II that PH ethics came into the limelight in Canada in the wake of a SARS
outbreak in 2003, which spurred efforts to renew the PH system and its infrastructure to be better prepared for the next PH crisis. SARS demonstrated that Canada was ill-prepared to deal with the ethical issues raised by serious epidemics (Singer et al., 2003). Some suggest that this history has repeated itself in the COVID-19 pandemic, which began in 2019 (Yu et al., 2020; Serebrin, 2021).

Canada has lagged behind the United States and the United Kingdom (UK) in the development of a focus on PH ethics, although Canadian ethicists have recognized the need for a “robust, coherent and meaningful ethic for public health” (Kenny et al., 2006, p. 402). Canadian feminist ethicists, through their theoretical work, have made important contributions to the broader development of PH ethics (Baylis et al., 2008; Kenny et al., 2010), particularly from a relational perspective. In fact, these authors have been widely cited since 2008. Several of the newer PH ethics frameworks contain relational principles proposed by these authors, such as relational autonomy and relational solidarity.

The most recent contribution to PH ethics in Canada was the development of several ethics frameworks by the national and provincial governments to guide decision making in pandemics. I discuss these in the final section of this chapter. The National Collaborating Centre for Healthy Public Policy, one of six PH collaborating centres in Canada, has established an extensive set of resources on PH ethics in general, and on ethics guidance for COVID-19 in particular. Other countries have also developed guidelines for action in a pandemic, as well as ethical decision-making frameworks.7

Kass (2004) described Stage III as the future of PH ethics, which she believed would revolve around three potential areas of concern: (a) public health research ethics; (b) environmental justice; and (c) global justice. She correctly predicted that ethics related to each of these areas would be the focus of debate and development in the future. Stage III encompasses the period from 2010 to the present day. In addition to the three areas of future concern identified by Kass, a number of other, perhaps smaller developments in PH ethics have emerged in this stage. Some important developments in this Stage III period include
1. *The availability of several new PH ethics frameworks for ethical analysis that are increasingly specific to PH aims.*
   Many of them include a broader range of principles (or normative criteria) more relevant to PH than the earliest PH ethics frameworks, which drew primarily on the four principles of health care ethics. Developers of these newer frameworks tend to draw from a wider theoretical and philosophical base; some of these frameworks are explicitly communitarian or include some communitarian principles (e.g., solidarity, relational autonomy, community participation). This was not the case with earlier frameworks (Baylis et al., 2008). Some Stage III frameworks also include methodological steps for ethical analyses that provide explicit guidance for ethical decision making. Such guidelines were absent from the earlier iterations.

2. *An expanded set of criteria to judge the adequacy of PH ethics frameworks.* The only authors found to provide such criteria in the early days of PH ethics were Kenny et al. (2006), who suggested five criteria that an appropriate PH ethics framework should meet. First, the framework should address the tension between PH and individual interests. Second, it should take into account the public interest and the common good. Third, it should clarify the relationship between PH and health care. Fourth, it should attend to the social determinants of health. Fifth, it should recognize the importance of reducing health inequities and attending to the most vulnerable. Additionally, Marckmann et al. (2015) proposed that a good PH ethics framework should have, at a minimum, two features: a clearly defined ethical foundation to ground it; and a systematic, methodological approach for applying ethical criteria.

3. *Movement away from the centrality of the classic tension or struggle in PH ethics over the importance of individual rights and autonomy versus the common good.* Many authors still refer to this classic tension, which is embedded in most of the earlier PH ethics frameworks. Prior to the COVID-19 pandemic, PH ethics had, in general, started to shift away from “its traditional concern with the tension between
individual autonomy and community health” (Lee, 2017, p. 5) toward recognition of the complexity of interconnections and our place among social and ecological systems. This balanced perspective is important in pandemic ethics because society’s response to a pandemic requires partnerships between PH and health care and reconciliation of the individual and the common good. Despite this shift, this tension has been a central ethical issue in the COVID-19 pandemic and the public’s response to restrictive PH measures (Woods, 2022).

4. A proposed merger between PH ethics, bioethics, and environmental ethics. In 2017, Lee proposed that insights from PH ethics, bioethics, and environmental ethics need to be brought together to help people address the complex and interconnected ethical issues in PH, health care, and the environment. PH ethics focuses on health at various levels, specifically individual health, community health, and environmental health. As a field, therefore, PH ethics provides a framework for integrating analysis across these levels of concern. As noted in point 3 above, ethicists in PH have been dissatisfied with what they see as the false dichotomy of individual rights versus community health, and are now considering and acting upon values that are based on an understanding of our interconnectedness with each other, animals, and the environment (Lee, 2017, p. 10). The One Health9 movement (El Zowalty & Järhult, 2020) is a reflection of this interconnectedness, as is global health and justice, and more recently, planetary health10 (Whitmee, 2015).

5. Movement away from a sole focus on distributive justice in PH ethics to include social justice as the moral foundation of PH ethics. As noted previously in the section above on “What is Public Health Ethics?” many authors in the field refer only to distributive justice as a principle in PH ethics (e.g., Childress & Garre Bernheim, 2015), despite arguments that social justice should be the focus in PH ethics (Powers & Faden, 2006). Close to 50 years ago, Beauchamp (1976) coined the term “public health as social
justice,” as noted in Wallack (2019), implying that PH practice, interventions, and actions, grounded in principles of social justice, aim to improve health and health equity. Thus, social justice is both a process and an outcome—as well as a central value and strategy—in PH (Wallack).

As mentioned above in the section “What is Public Health Ethics” (para. 5), many have argued that there needs to be more than distributive concerns in applying the principle of justice in PH (Moroni, 2020; Rogers, 2006; Young, 1990). For example, in a study in Alberta regarding immunization policy during the H1N1 pandemic in 2009, the authors demonstrated the predominance of distributive justice principles and the resultant problems associated with this view of justice. They argued that distributive justice caused difficulties for vulnerable groups and suggested that policymakers use a social justice approach as an alternative to distributive justice in pandemic immunization policy (Torrie et al., 2021).

6. A significant focus on PH ethics in a pandemic (or “pandethics” as coined by Selgelid [2009]). Several epidemics and pandemics have afflicted the world since the turn of the 21st century (e.g. SARS, H1N1, avian influenza, Ebola). Many authors have suggested that specific countries, and the world at large, were not adequately prepared for COVID-19 (Fairchild et al., 2020; Yu et al., 2020), despite warnings from WHO and PH experts. Thus, some countries—including Canada, the US, and the UK—have developed ethics frameworks and pandemic plans for guiding their responses to COVID-19. Around the world, governments have struck national and international committees and commissions to advise them on the local, national, and global responses to COVID-19. In addition, researchers globally have been conducting considerable research on all aspects of COVID-19. Ethical issues related to the pandemic are front and centre in the news, in conversations, and on social media.
In the following two sections, I discuss recent developments in Kass’s three areas of concern for the future of public health ethics (public health research ethics, environmental justice, and global justice). In many ways, these three areas intertwine. Global justice encompasses the issue of global health equity as well as the ethics of global health and justice. Environmental justice interconnects with environmental health and environmental health ethics, as well as global justice, global health, and global ethics. Public health research ethics applies to research on global and environmental health in the context of public health, and all of these have implications for justice.

**Public Health Research Ethics**

Kass (2004) discussed public health research ethics only briefly, but she believed that a central question would be whether ethical requirements for public health research should differ systematically from ethics requirements for other types of research involving human subjects. Several authors have since taken up this question (e.g., Bromley et al., 2015; Taylor, 2019). Although Kass acknowledged that much public health research would resemble other research in the intent to develop generalizable knowledge, she argued that conceptually, public health research is different in that it often involves the whole community or the population to be its “patient.” This unique characteristic has different demands for ethical analysis. Kass’s question has still not been resolved, nor have existing ethics guidelines for research fully addressed it (e.g., TCPS 2, 2018; the *Belmont Report*, 1979). The authors mentioned above have studied ethical issues in public health research with communities or populations as a whole, especially given the evolution of community-based participatory research (CBPR) (Banks et al., 2017; Wallerstein et al., 2017) in which the community as a whole is a primary stakeholder.

In Canada, the federal government established a Panel on Research Ethics (PRE) in 2001 (Panel on Research Ethics, 2022). This panel, in turn, struck an expert committee in 2014 (the Population and Public Health Research Advisory Committee [PPHRAC]) to advise on issues specific to the ethics of population and public health research (MacDonald, 2015b). The rationale emerged from a view within the public health community that the *Tri-Council Policy Statement on the Ethical
Conduct of Research Involving Humans (TCPS 2) did not specifically address all relevant ethics issues related to research in population and public health (PPH). I had the privilege of sitting on that expert committee. The aims of the PPHRAC were “to identify key ethics issues in these fields of research, help craft ethics guidance in response to these issues, and advise on how such guidance could best be integrated into the TCPS 2” (MacDonald, 2015b, p. 7).

Despite my involvement in developing that guidance, I no longer believe that the committee fully addressed all the relevant ethical issues for PPH research. The main findings of the PPHRAC were that the TCPS 2 guidance, as it stands, is applicable to PPH research, but that examples and clarifications were necessary regarding some ethics-related aspects. These changes have been added to the 2018 version of the TCPS 2. One such area clarifies that, for PPH research, prior informed consent is not required in situations in which obtaining consent will preclude answering the research question. For example, an exception to the requirement for informed consent would be a situation in which a cluster-randomized trial is used to compare two different community-wide “stop smoking” campaigns in two separate communities. If informed consent was required in this situation, community members would be alerted to the presence of the campaigns, and this knowledge could affect the group response, creating validity problems. Thus, the research question could not be answered under these circumstances (TCPS 2, Article 3.7A, 2018).

Another addition was a clarification of the difference between observational research, as defined in the TCPS, and epidemiological observational research. Observational research, in general, refers to studies in which the behaviour and talk of participants are observed in natural settings (Jangiani et al., 2019), and can be qualitative in nature. Qualitative observational studies are different from the category of observational studies (non-experimental research designs) used in epidemiology (Mays & Pope, 1995). In epidemiological observational research,

an investigator observes what is occurring in a study population without intervening. Sometimes these are called natural experiments. Observational studies may be
descriptive or analytic. Examples of analytic studies include case-control, cohort, cross-sectional, and ecologic studies, as well as hybrid designs and the data are often quantitative. (Kelsey, 2008, p. 609)

Taylor et al. (2016) have pointed out that there are ethical issues in PH research that are not considered in traditional human research guidelines. For example, the revised TCPS 2 does not fully address the nature of community engagement in research, and how researchers should work in and with the community. In such a situation, the subject is often not an autonomous individual, but an entire community or population group. Taylor and colleagues (2016) argued that current regulatory frameworks do not provide sufficient moral guidance for researchers conducting primary prevention research in community settings, where the entire community is a stakeholder and outcomes are at the community level. They suggested that communities, not just individuals, have interests and rights that researchers must take into account.

The corresponding researcher duties in this type of investigation include duties to respect the community, to do no harm to the community, and to benefit the community. These duties, however, do not readily translate to similarly worded duties owed to individual research participants. In the 2018 TCPS 2, the focus seems to be primarily on individuals as research subjects or participants, and does not include harms or benefits at the community level.

The exception to this is Chapter 9 of the TCPS 2, “Research Involving the First Nations, Inuit, and Métis Peoples of Canada,” in which the rights and welfare of Indigenous communities as a whole are acknowledged. The chapter’s main principles include the need for researchers to engage with the community; to balance individual and collective interests; to respect codes of research practice that go beyond the scope of ethical protections to individual participants; and to acknowledge the important role of Indigenous communities in promoting collective rights, interests, and responsibilities that also serve the welfare of individuals.

This chapter in the TCPS 2 is directed specifically at investigators doing research in Indigenous communities. Thus, it may not be read or considered by PPH researchers doing research in non-Indigenous communities.
communities. I argue that in a public health research context, the TCPS 2 needs to provide guidance for research with communities as a whole that may comprise populations other than Indigenous Peoples.

Another issue that has implications for ethics in public health research is the emergence of, and increase in, community-based participatory research (CBPR). This type of investigation focuses on research subjects with lived experience of the phenomena under study, or people who have responsibility for such populations (for example, members of community agencies). Rather than being “subjects,” they are understood to be active participants who are involved at every stage of the research process. In most nursing research, and in much qualitative research, investigators generally do not use the word “subjects,” but instead refer to “participants.” This shift in role from subject to participant raises several ethical challenges. Bromley et al. (2014) identified and categorized several challenges that reflect some very difficult-to-manage issues that are not generally included in ethical guidance from research ethics review boards. For example, the shift from subject to participant “calls into question current understandings of consent and autonomy” (p. 907). Consent may be required from the community as a whole, as represented by community leaders who have authority to speak for the community in consenting to research. In CBPR, participants are both individual and collective actors, and yet ethics review boards often “sidestep this difference between individual and collective identities and do not resolve the question of who can decide for whom in research” (p. 907).

Buchanan and Miller (2006) examined the implications of the moral imperative in public health to protect population health, and raised questions about the appropriate norms to guide research ethics in this context. The authors argued that taking a public health perspective on research ethics means “broadening the conceptualisation of risks and benefits deemed ethically relevant in deliberations on health research” (p. 730). Researchers must identify benefits and risks not just for individual research participants, but also for the population or community as a whole. Examples of community risks may include the stigmatization of communities on the basis of the research findings, or community economic losses. These issues are not, in my view, adequately addressed in the TCPS 2 guidelines or in...
the relevant guidelines of other countries (e.g., the US Belmont Report [1979]).

How should researchers account for community in their consideration of PH ethics? Taylor (2019) suggests that the conventional application of research ethics to PH research is unlikely to account for the risks and benefits at the community level, producing avoidable harm to the whole community (for example, negative attitudes and beliefs about the community). Many PH researchers in the United States find the Belmont principles relevant to their work, but insufficient in that the principles fail to include the community as a key stakeholder in the research (Taylor, p. 9). Taylor suggests that the principle of community should be a critical and necessary addition to the Belmont principles. In turn, I would argue that we should also add it to Canada’s TCPS 2. The following Ethics in Practice case is an example of how communities are dramatically affected by the ethical decisions that are made by public health care researchers.

**ETHICS IN PRACTICE 4-3**

*Communities Experiencing High Rates of HIV, Substance Use, and Overdose Deaths*

There are two cities in a Canadian province, each with a large community in the inner city core, that have sizeable populations experiencing high rates of HIV infection, substance use, and overdose deaths. Many of these people are also homeless. Two independently established organizations of peers, with lived experience of these issues, provide counselling and support to the populations in each city. Each of these groups works in collaboration with a community centre in their city to support the population experiencing homelessness through provision of meals, health care, transitional housing, and addiction services. A team of harm reduction researchers working in a university research centre wants to conduct a cluster-randomized trial in the two cities to compare the effects of two evidence-informed, community-wide interventions to reduce the incidence of HIV infection, substance use, and overdose deaths in these communities.

**REFLECTIVE QUESTIONS**

1. *What research approach is appropriate for such a study?*
Environmental and Global Health, Justice, and Ethics

In this section, I combine discussion of specific topics raised by Kass (2004)—about environmental and global health, justice and ethics—because they are intertwined and difficult to separate. These topics are also rife with disagreement and controversy, and the challenges of addressing them are so extensive that it will take massive efforts on the part of nation states at a global level. Even though Kass (2004) identified them as future issues in PH ethics, the future is now, and the questions these topics pose are far from being resolved. Unfortunately, progress in addressing environmental and global ethics and justice has been limited.

Environmental health is one of the main branches of PH that focuses on the relationships between people and their environments. In environmental health, the aim is to promote human health and well-being and ensure safe and healthy communities. Practitioners work to advance policies and programs to reduce chemical and other environmental exposures in air, water, soil, and food to protect people and provide communities with healthier environments.

Environmental ethics is the study of ethical questions raised by human relationships with the non-human environment, including nature and animals (Palmer et al., 2014). Environmental ethicists identify reasons why non-human nature, species, and ecosystems have inherent value. As such, their worth cannot be reduced to economic value or other instrumental value that serve only the needs of the human species. As Palmer suggested, “Many environmental issues are as much ethical issues as they are economic or legal issues” (p. 421). Within environmental ethics, there are contrasting views about the main problems in the field,
and questions about how they should be addressed. Many PH and environmental ethicists (e.g., Kopnina et al., 2018) believe that anthropocentric attitudes, that is, “the belief that value is human-centred and that other beings are means to human ends” (p. 109) are a cause of our environmental problems, and that “anthropocentrism is at the root of our ecological crises” (p. 109).

Environmental justice, defined simply as “equitable exposure to environmental good and harm,” (Stewart, 2020, p. 111), began as a social movement in the 1970s in response to environmental pollution and toxic waste dumping in racialized communities and poor neighbourhoods. Key principles of environmental justice include, but are not limited to: (a) ecological unity and an understanding that all species are interdependent; (b) the right to ethical, balanced, and responsible land use; (c) the right to political, economic, cultural, and environmental self-determination; (d) cessation of hazardous waste production; (e) accountability on the part of current and past producers of such wastes for detoxification and containment; (f) the right of workers to a safe and healthy environment; and (g) the right of victims of environmental injustices to reparations for damages (Ramirez-Andreotta, 2019).

Given the existing problems of increasing urbanization, globalization, and environmental degradation, the meaning of environmental justice has expanded to include generational and global environmental justice (Bolte et al., 2011). This expansion connects environmental justice to global health and ethics. Of all the global justice issues, however, one of the most significant and visible is that of global poverty, which our current global order has caused and perpetuated (Brock, 2021). It has also created considerable health inequities across the world.

Even more important in the context of planetary health is the issue of climate change and climate justice. Many believe climate change to be the most significant global, health, justice, and ethical issue facing the world. In 2015, *The Lancet* journal published an extensive report, “Safeguarding Human Health in the Anthropocene Epoch: Report of the Rockefeller Foundation – Lancet Commission on Planetary Health” (Whitmee et al., 2015), which described the state of the planet’s health at the time and what would be required to address the problems. The authors laid out, in
stark relief, the future ethical issues we are facing as a species. While Benetar et al. (2003), and many others in the scientific community, argued for urgent action almost 20 years ago, little progress has been made.

The current global context includes rapid advances in science and technology, growing health inequities, increasing levels of extreme poverty, inequities in patterns of health care expenditures across the globe, and population growth, with its attendant increase in overconsumption and environmental degradation. In light of this, Benatar et al. (2003) argued convincingly for the importance of global health ethics when considering environmental justice. They made very clear the ethical challenges for which solutions are essential to prevent massive displacement, rebellion, and violence from those disenfranchised groups that are systematically excluded from the benefits that others have achieved, and those who may experience the negative consequences of environmental degradation (MacDonald, 2015b).

**Some Useful Frameworks for Analyzing Public Health Ethical Issues**

Early PH ethics frameworks were developed to help practitioners and PH leaders analyze PH issues and guide ethical decision making in specific situations. As mentioned previously, some of the early frameworks used for PH ethics drew on the four basic principles of bioethics (autonomy, beneficence, non-maleficence, and justice) (Beauchamp & Childress, 1979), with some modification to make them fit for the PH issue at hand. The frameworks developed after 2010, and particularly after 2015, were more likely to reflect the moral aims of PH, with principles that were relevant and specific to the practice of PH.

In MacDonald (2015b), I conducted a detailed comparison and evaluation of eight early PH ethics frameworks. I explained various categorizations of PH ethics frameworks and compared them on the PH issue addressed, the principles and process, and the theoretical foundation. I also critiqued these frameworks. I did a second comparison of the frameworks using the five criteria for judging framework adequacy by Kenny et al. (2006). Although these are
older frameworks, they may still be relevant to use for resolving some PH ethics issues today. However, a new evaluation and critique of recent PH ethics frameworks containing principles more reflective of PH values would likely be more helpful in resolving current ethical dilemmas.

What Are the Ethics of Pandemics?

Responding to pandemics is a PH issue on local, provincial, national, and international agendas. Although I mentioned earlier in this chapter that there had been a shift in PH ethics away from the classic tension between the individual and the common good toward balancing the two concerns, the COVID-19 pandemic has revived this paradigm struggle in PH. Because we can expect more pandemics in the future, this tension will continue to be raised. The WHO (2007) has predicted that we can expect to experience at least three pandemics per century, at intervals of 10 to 50 years; however, it is uncertain whether that timeline is speeding up, given the fact that three pandemics have recently occurred within a 20-year span (SARS in 2003, H1N1 in 2009, and COVID-19 in 2019). Although not all serious epidemics become pandemics (e.g., H7N9 [avian influenza], Middle East Respiratory Syndrome [MERS], H5N1 [another avian influenza]), these outbreaks were still serious enough to generate considerable worry given the high mortality rates associated with them (H7N9 39.3%; MERS 34.4%; H5N1 52%) (Atlas Magazine, 2020).

The SARS and H1N1 pandemics gave only a taste of the impact of a pandemic on countries and citizens of the world. In those past pandemics, North Americans and Europeans experienced very few of the PH containment measures that have occurred with COVID-19, such as social distancing, mask wearing, quarantine, travel restrictions, business closures, and restrictions on public and private gatherings. More recently, we have experienced challenges with the rollout of a vaccination strategy accompanied by the requirement for vaccine passports as proof of immunization.

Despite broad public support for PH measures, a sizeable segment of the population opposed many of these containment strategies, which led to protests and demonstrations across Canada.
and around the world. What seemed unique about this pandemic was that there was considerable disagreement within the population about both the effectiveness and legitimacy of the PH measures. Social media contributed to the spread of much misinformation about COVID-19, its treatment, and the PH response, which allowed for rapid promulgation of conspiracy theories. There was also considerable disagreement among scientists about these issues, and some argued that the evidence was conflicting (Angeli et al., 2021; Dahlquist & Kugelburg, 2021).

In fact, a study by European researchers defined the COVID-19 situation as a full-fledged policy “wicked problem” (Angeli et al., 2021, p. 1). This study involved an ethical analysis of the two scientific views that were put forth during the COVID-19 pandemic: the Great Barrington Declaration (Kuldorff et al., 2020) and the John Snow Memorandum (Gurdasani et al., 2021). These two scientific petitions, signed by credible scientists, translated the same scientific evidence into polar opposite advice regarding COVID-19 response policies (Angeli et al., 2021).

This discrepancy occurred because, as Angeli and colleagues (2021) argued, each group used a “different ethical compass,” in which various ethical values were given different weights by each group. The Great Barrington proponents (Kuldorff et al., 2020) argued against a lockdown approach, favouring a containment approach that focused on the most vulnerable and imposed only limited restrictions on the majority. The John Snow group (Gurdasani et al., 2021) instead argued for continuing restrictive lockdown measures on everyone.

Angeli et al. (2021) recommended that a situated policy approach was required in this situation, involving consideration of the socio-cultural and socio-economic context. Such consideration may lead to different conclusions and strategies in different contexts. They argued that a one-size-fits-all approach cannot work in all circumstances. The investigators illustrated how disagreement on policies could evolve within different scientific communities based on the values held by the various parties to the disagreement.

In my analysis of pandemic plans (MacDonald, 2013), several ethical challenges emerged in relation to pandemic planning that also have continued relevance for the COVID-19 pandemic response.
These challenges include: (a) allocating scarce resources for both prevention and treatment (e.g., vaccines, anti-virals, ventilators, personal protective equipment [PPE], and hospital beds, particularly ICU beds); (b) obligations of health care workers to provide care in the face of risk to self and family, and the reciprocal obligations of organizations to their workers; (c) implementing restrictions and social distancing measures for individuals and groups (e.g., isolation, quarantine, restrictions on travel and movement, closure of public spaces, and limits on public and private gatherings); and (d) obligations of countries to one another in pandemic responses. Because infectious agents do not honour national boundaries, as we have seen, poor containment in one country can have serious global consequences.

During the COVID-19 pandemic in Canada, one particular containment measure had serious economic consequences. This was the mandated closure of some types of businesses because of the risk of widespread disease transmission (e.g. restaurants, gyms, recreational facilities, hair and nail salons, etc.). This did not occur during either the H1N1 or SARS pandemics, perhaps because the duration of these smaller pandemics was much shorter, and economic adversities did not have time to develop. In addition to the businesses mandated to close during the COVID-19 pandemic, there were many other closures due to lack of staff and other factors that impeded the ability of businesses to carry on with regular activities. For example, by September and October of 2020, two thirds of businesses in Canada had laid off half or more of their staff. Approximately one third did not know how much longer they could operate (Leung, 2021).

Another restrictive control measure that had difficult consequences for many was the closure of schools at all levels. At the elementary level, school closures had mental health impacts on students, and economic impacts on parents who had to stay home to care for their children and could not go to work. Although “work from home” strategies helped to offset this, the impacts were debated (Edwards, 2022). The closure of churches, synagogues, mosques, and other places of worship was devastating for many of my own friends, acquaintances, and community members. It seems likely that this was true for many others in the population.
Some Public Health Ethics Frameworks for Managing COVID-19

Canada and other countries developed guidelines for managing the pandemic in the form of ethical decision-making frameworks. Given the evidence that scientists interpret data in relation to the ethical values they hold (Angeli et al., 2021), it is worth exploring the values contained in these frameworks to determine whether and how these values are a fit with the necessary considerations in PH. Do they contain values and principles that are relevant and important to the values and aims of PH?

In the four sections below, I briefly summarize the values and principles contained in four Canadian ethical decision-making frameworks for COVID-19 and/or other pandemics, exploring their relevance to PH. I have italicized these values and principles in the sections below to bring them to the attention of readers. They are also explained in more detail in Appendix 4-1, which provides a summary of the frameworks from the Governments of Canada, British Columbia (BC), Alberta, and Ontario.

Government of Canada

The Government of Canada (2021) Public Health Ethics Framework: A Guide for Use in Response to the COVID-19 Pandemic in Canada contains values that are relevant and specific to the moral aims of PH. The two foundational principles or values are trust and justice. In this context, justice should be understood to primarily refer to distributive justice, but aspects of social justice may be implied in the framework’s focus on equity versus equality. In aiming to eliminate inequities in the burdens of pandemic restrictions on the population, the framework encompasses structural considerations and thus, the principle of social justice. This is suggested in the statement that attention should be paid to those most vulnerable to injustice, or those disproportionately affected by the pandemic.

The principle of respect for persons, communities, and human rights in the framework goes beyond the usual focus on individual autonomy because it includes the community as a whole, and thus could reflect relational versus individual autonomy with respect to
the community. Inclusion of this principle also acknowledges the need to respect the rights of Indigenous communities—again, moving beyond an individual focus. This framework also incorporates the *precautionary principle*, an important concept in PH that has only been included in PH ethics frameworks since about 2015. In the principle *promoting well-being*, the community is included, unlike in most early PH ethics frameworks. The principle of *working together* could be interpreted as reflecting the notion of *solidarity*, another important principle in PH ethics that has emerged in recent frameworks. Working together also reflects a relational understanding of persons as part of the greater whole. The principle of *intersectionality* (i.e., applying an intersectional lens), which encompasses and promotes social justice, has also been included.

**Government of British Columbia**

The BC *COVID-19 Ethical Decision-Making Framework* (BC Provincial COVID-19 Taskforce, 2020) includes similar principles to the other three frameworks. In keeping with Kenny et al.’s (2006) criteria for the adequacy of a PH ethics framework, this framework helps us distinguish between PH and clinical ethics. Respect is one of the framework’s key principles, but unlike in the Government of Canada framework, only individual respect is mentioned. There are no principles that focus on doing good (often referred to as “beneficence”), although most PH ethics frameworks include it. There is reference to the *harm principle*, which reflects the paradigm tension between promoting community versus individual health and possibly impinging on individual rights. Most writers of recent PH ethics frameworks now propose finding a balance between individual and collective rights rather than prioritizing one over the other, as discussed earlier in this chapter under point 3 of the “What Is the History of Public Health Ethics?” section. The principle of *fairness* (justice) is included, and encompasses both *equality* (everyone matters equally) and *equity* (those who most need resources ought to receive them preferentially). A utilitarian view on justice is reflected in the principle that resources should be distributed to achieve the greatest good for the greatest number. *Cultural safety* is
an important substantive principle, which is not generally seen in most PH ethics frameworks, but is included in this one.

Working together is also included as a principle within procedural considerations, along with the principle of solidarity. Solidarity, however, is often viewed as a substantive principle in other frameworks. Here, solidarity is a concept inherent in the notion of “calculus of consent,” in which questions such as “Why should I care? Why should I help? Why should I contribute to the public provision of others?” are asked of ourselves and others to justify why we should follow laws, rules, and policies (Jennings & Dawson, 2015, p. 31).

The BC framework is an eight-step methodological framework, in keeping with Marckmann et al.’s (2015) criteria for the adequacy of a PH ethics framework. Overall, this BC framework is quite reflective of many PH values, although it is not as reflective of PH ethical values as those found in the Government of Canada framework.

**Government of Alberta**

*Alberta’s Ethical Framework for Responding to Pandemic Influenza* (Alberta Health, 2016) focuses on pandemics in general, not just COVID-19. The Government of Canada and British Columbia frameworks specify both substantive and procedural principles and values. Alberta does not discuss them separately, although the framework does include both. Some of the procedural principles are included under the value of *making good decisions*. A weak version of solidarity is inherent in the principle of respect, as is equity, although under the principle of fairness, it seems that in the framework equity and equality are conflated. A positive aspect of this framework is that there is an attempt to balance individual rights and societal need. In the principle of working together, there is a weak implication that it is related to solidarity. In the framework, the concept of inclusiveness relates to the principle of participation, which was rarely included in early public health ethics frameworks, but is appearing more frequently in newer PH ethics frameworks.
Government of Ontario

The Government of Ontario’s (2020) Ethical Framework for COVID-19 Vaccine Distribution is not specifically concerned with COVID-19’s ethical considerations. Rather, it aims to guide decisions regarding the prioritization and distribution of vaccines, making it a narrower and more limited framework than the other three discussed here. Like the Alberta framework, there is more focus on equality over equity, although it appears that equality is understood as equity despite differences in meaning. There is a limited focus on solidarity—within the understanding of working together—in comparison to other frameworks. However, the authors do suggest that using all the principles will “advance relationships of social cohesion,” (Public Trust, para. 1) which may be seen as reflecting the principle of solidarity. Including affected parties in the decision making is identified as important, and, therefore, may be seen as supporting participation.

Conclusion

Public health ethics has come a long way in the past four decades, with extensive theoretical and empirical work being conducted internationally, as well as in Canada. The National Collaborating Centre for Healthy Public Policy (NCCHPP) in Quebec, one of six National Collaborating Centres for Public Health, has been curating and developing an extensive array of materials and resources to help build the capacity for PH ethics in Canada. These include an online course and a range of diverse publications, presentations, webinars, and videos on PH ethics. I encourage anyone interested in PH ethics to browse the ethics section of the NCCHPP website (NCCHPP, n.d.).

Developments in the philosophical underpinnings of PH ethics and frameworks to guide practice and decision making have been substantial, with an expansion of the range of philosophies and theories and a large increase in the number of ethics frameworks explicitly oriented towards PH. Although many ethics frameworks remain grounded in liberalism, more communitarian frameworks
have emerged, as well as frameworks with a broader range of principles and values relevant to public health.

PH nursing ethics, although it has been expanding, continues to lag behind developments in nursing, feminist, and PH ethics. Nonetheless, the 2017 CNA Code of Ethics includes more content relevant to PH nursing ethics than previous versions. I suggest that concerted work to foreground PH nursing ethics in conjunction with these other developments would be useful. In particular, PH nursing ethics frameworks are needed that build on the insights found in feminist relational theory, nursing ethics, and PH ethics; such frameworks ought to be focused on the unique ethical challenges experienced by PHNs. To support this work, more research is necessary to clarify the nature of the ethical challenges public health nurses experience when working with communities and populations, as distinct from the ethical challenges of nurses working in institutional settings with individuals. Attention to PH ethics education for PHNs, as well as PH practitioners in general, is important to ensure that there is capacity in the workforce to deal with the ethical challenges in PH practice.

A great deal more work in public engagement is necessary to inform the values underlying PH ethics, particularly for managing public health emergencies. The COVID-19 pandemic has made clear that many in the population do not understand the legal, ethical, and historical basis for managing the challenges of a pandemic in ways that address the paradigm tension in PH between the individual and the common good, or in ways that promote population health, relational justice, solidarity, and equity.

In the second edition of Toward a Moral Horizon: Nursing Ethics for Leadership and Practice (Storch et al., 2013), I concluded Chapter 20 with a long list of PH ethics issues for the future, many of which remain current today. The updated list includes: (a) defining societal versus individual responsibility for health; (b) understanding the relationship between health and human rights at the population level; (c) priority setting in public health; (d) cost-effectiveness analysis and its inability to take equity into consideration; (e) the relationship between health and economic development; (f) ethics in emergency humanitarian interventions; (g) environmental and global justice; (h) global aging; (i) global health equity;
(j) planetary health; (k) population and public health research ethics; and (l) public health system reform.

While ethical analyses have been limited for many of these issues to date, the list above provides a useful agenda for further development in the field of PH ethics. With respect to the items on this list, it will be important for nurse ethicists to continue to identify and define the ethical implications for public health nurses in order to advance the field of PH ethics in nursing.

QUESTIONS FOR REFLECTION

1. How might you reconcile the individualist focus of most human rights approaches with the collectivist or population focus of public health ethics? Is it possible to reconcile a concern with individual human rights and population level or public health ethics?

2. How does this chapter provide you with guidance in thinking about pandemic responses for the future?
Endnotes


2 I have organized the current chapter in much the same way as in the second edition of this text (Storch et al., 2013), with similar headings that define public health, the meaning of “the public” in public health, the history of public health ethics, ethics in public health nursing, and ethical concerns in a pandemic.

3 Childress et al. (2002) have conceptualized three notions of public: the numerical public, the political public, and the communal public. I previously explored these three notions of public and discussed an evocative understanding of the public by Jennings (2007). (See MacDonald 2013 and 2014 for this discussion).

4 For a discussion and critique of the philosophical and theoretical basis for PH ethics, please refer to two earlier publications (MacDonald, 2013, 2015a), in which I explored the liberal foundations of PH ethics in utilitarianism, contractarianism, and rights-based approaches and discussed the emergence of communitarian perspectives in PH ethics. Drawing from a framework by Jennings (2003), I discussed how various strands of ethical and political theory connect and have implications for PH ethics. I reviewed a range of core ethical concepts from civic republican and communitarian traditions and discussed their implications for PH ethics. Finally, I explored different understandings of liberty in the liberal and communitarian traditions.

5 G. Rose, in his landmark Strategy of Preventive Medicine (1992) explained the paradox between the two main preventive approaches to a disease, the individual- and population-based.

6 Please refer to Chapter 1 in this book.

7 An article in which I analyze several recent PH ethics frameworks published since 2015 is currently under development.

8 I used their criteria to evaluate eight PH ethics frameworks, as noted in Appendix 2 in MacDonald (2015b).

9 One Health is an approach that recognizes that the health of people is closely connected to the health of animals and our shared environment (Centers for Disease Control and Prevention, 2022).

10 Planetary health is “the achievement of the highest attainable standard of health, wellbeing, and equity worldwide through judicious attention to the human systems—political, economic, and social—that shape the future of humanity and the Earth’s natural systems that define the safe environmental limits within which humanity can flourish. Put simply, planetary health is the health of human civilisation and the state of the natural systems on which it depends” (Horton & Low, 2015).

11 For a detailed essay about the precautionary principle as it applies to public health, please see Beloin (2009).

12 Intersectionality, a broad theoretical perspective, provides a way to understand how multiple social identities (e.g., gender, race, disability, sexual orientation, etc.) intersect at the level of the individual or group and reflect social constructions of oppression and privilege (Bowleg, 2012). It is a framework that
Toward a Moral Horizon
accounts for the synergistic or amplifying effects of multiple forms of oppression (Betker et al., 2019).

References


Chapter 4: Exploring Public Health Ethics


World Health Organization. https://www.who.int/europe/publications/i/item/9789289054126


Chapter 4: Exploring Public Health Ethics


Chapter 4: Exploring Public Health Ethics


Yu, A., Prasad, S., Akande, A., Murariu, A., Yuan, S., Kathirkamanathan, S., Ma, M., &
APPENDIX 4-1

Canadian Frameworks for Responding to the COVID-19 (or Another) Pandemic
<table>
<thead>
<tr>
<th>CANADA (PUBLIC HEALTH AGENCY OF CANADA)</th>
<th>BRITISH COLUMBIA</th>
<th>ALBERTA</th>
<th>ONTARIO</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PURPOSE</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>• For policymakers &amp; PH professionals making decisions in the context of COVID-19</td>
<td>• To ensure ethically defensible decision making</td>
<td>• To provide a resource for planners and policy makers to consider ethical implications of the choices they make related to responding to a pandemic</td>
<td>• To guide decisions about COVID-19 vaccine prioritization and distribution decisions</td>
</tr>
<tr>
<td>• To ensure integration of shared values into decision making</td>
<td>• To serve as a transparent guide before, during and after pandemic</td>
<td>• To ensure integration of shared values into decision making</td>
<td>• To provide a resource for planners and policy makers to consider ethical implications of the choices they make related to responding to a pandemic</td>
</tr>
<tr>
<td>• Contribute to improved health outcomes and service delivery</td>
<td>• Increase public awareness, confidence and preparedness</td>
<td>• Contribute to improved health outcomes and service delivery</td>
<td>• Increase public awareness, confidence and preparedness</td>
</tr>
<tr>
<td>• Respect</td>
<td>• Trust and justice</td>
<td>• Respect</td>
<td>• Minimize harms &amp; maximize benefits</td>
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<td>• Respect for humans, communities, and human rights</td>
<td>• Respect for humans, communities, and human rights</td>
<td>• Respect for humans, communities, and human rights</td>
<td>• Respect for humans, communities, and human rights</td>
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<tr>
<td>• Promotion of well-being</td>
<td>• Promotion of well-being</td>
<td>• Promotion of well-being</td>
<td>• Promotion of well-being</td>
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<tr>
<td>• Minimizing harm (effectiveness, proportionality, reciprocity, precaution)</td>
<td>• Minimizing harm (effectiveness, proportionality, reciprocity, precaution)</td>
<td>• Minimizing harm (effectiveness, proportionality, reciprocity, precaution)</td>
<td>• Minimizing harm (effectiveness, proportionality, reciprocity, precaution)</td>
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<td>• Working together</td>
<td>• Working together</td>
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<tr>
<td>• Respect</td>
<td>• The harm principle</td>
<td>• Respect</td>
<td>• Equity</td>
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<tr>
<td>• Fairness</td>
<td>• Fairness</td>
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<td>• Least coercive &amp; restrictive means</td>
<td>• Least coercive &amp; restrictive means</td>
<td>• Least coercive &amp; restrictive means</td>
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<td>• Working together</td>
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<td>• Reciprocity</td>
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<td>• Proportionality</td>
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<tr>
<td>• Flexibility</td>
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<td>• Flexibility</td>
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<tr>
<td>• Making good decisions</td>
<td>• Making good decisions</td>
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</table>
PROCEDURAL PRINCIPLES/VALUES

• accountability
• openness & transparency
• inclusiveness
• responsiveness
• intersectionality

PROCESS

1. Identify issue, gather facts
2. Identify & analyze ethical considerations, prioritize values & principles
3. Identify and assess options in light of values and principles
4. Select best course of action & implement
5. Evaluate

1. Define the issue
2. Clarify the facts if possible
3. Identify stakeholders & perspectives
4. Identify & analyze principles & values
5. Identify alternative courses of action in light of values
6. Make a decision
7. Implement decision
8. Review & document decision

1. Follow ethical considerations worksheet in which the principles/values are considered for three different options (to be selected)
2. Fill in summary of decisions worksheet for the following:
   • the question being addressed
   • recommendations
   • this allows us to best...
   • this solution does not...
   • justification

No specific steps are specified other than a general directive to take the principles into account, follow human rights legislation, and take additional steps necessary to prevent and treat COVID-19 among vulnerable groups.
“We are told that decolonization will not occur through discourse alone. The ethical path forward is action. Take what you have heard and build towards change.”

[Editors’ note: This chapter is presented by five Indigenous authors using a style that reflects their positionality and expertise in regard to Indigenous perspectives about nursing ethics. The chapter begins with rich narratives written by each author to contextualize their discussions, which follow in the Circle video and its accompanying transcript.]
Bios/Positionality

**Leanne Poitras Kelly**

*Taanshi!* Leanne Poitras Kelly *dishnihkaashoon* and I am the youngest of seven children, born in Balcarres, Saskatchewan to Rose Amyotte and Alexander Poitras. Both of my parents are Métis-Cree from Saskatchewan. My mother was born in the area known as Katepwa, where I continue to return to feel whole, and my dad was born in the area known as Tullymet, his family having migrated from the Métis community of Turtle Mountain, North Dakota. Both were from Road Allowance families and like many Métis made a living travelling for work and finding community among other Métis families. My maternal line of ancestor names include Racette, Cardinal, and Bellegarde. The women of my Poitras line had the family names of Jeunotte, Ross, and Laverdure. I speak the names of my ancestral line as it reclaims and positions Métis as present in this country for generations. It creates visibility in the face of invisibility. I have been a nurse for over thirty years and worked predominantly in First Nations communities. I am currently a PhD candidate and instructor at the University of Victoria School of Nursing.

**Mona Lisa Bourque Bearsink**

*nitisiyihkâson amiskosâkahikan nêhiyaw peyakôskân, ostêsimâwoyasiwêwin nikotwâsik ohci niya kayahô. Born into the Bearsink family from Beaver Lake Cree Nation, in Treaty 6 Territory, I identify with my matrilineal side, nîhkom* Marianne Bearsink *nikawiy* Elma Bourque Bearsink, as a means to recognize the long-standing rematriational strength, resistance, and tenacity I originate from. In recognizing the long-standing line of women I come from, I acknowledge my father, a settler from the Langevin family, with deep roots in historical violence played out in the residential school policy. I have never known him, but through stories I learned of the deep compassion he had for those who were not treated with dignity. His own social suffering was rooted in deep love for *nikawiy*, where my own critical
insights and love of nursing was born, and thus shaped who I am, where I come from and what I stand for today. As a mother my children (two sets of twins) are at the heart of my existence and expression of love. As an Associate Professor at Thompson Rivers University, and an inaugural Canadian Institute of Health Research-Institute of Indigenous Peoples Health (CIHR-IIPH) Chair holder in Indigenous Health Research for Nursing in British Columbia, I am leading community knowledge as a generative process in advancing Indigenous health nursing research.

**Lisa Perley-Dutcher**

*Wolastoqi ehpit nil/* I am a Wolastoqiyik/Maliseet woman, and the daughter of Carol Sappier and Raymond Perley, both from Neqotkuk/Tobique First Nation. In my youth, I was rooted in social activism, as several women in my family and community led the way in helping to change the *Indian Act*'s removal of status from women who married out. My partner Stephen, our four sons, and our four granddaughters keep me grounded in love. I worked as a registered nurse for 30 years in a variety of capacities and completed my master’s degree in nursing from the University of New Brunswick (*UNB*) in 2012. A major focus in my career has been contributing to positive health outcomes for Indigenous Peoples and promoting cultural competency/safety practices of health care providers. I have been a coordinator of the Home and Community Care Program, the first *UNB* Director of the Aboriginal Nursing Initiative, Indigenous Services Canada Atlantic Director of Mental Wellness, and president of the Indigenous Nurses Association of Canada. I am currently leading Wolastoqey language revitalization by establishing the first Wolastoqey immersion land-based education program in Wolastoqey territory.

**Bernice Downey**

*Aanii! Boozhoo! I am an Anishinaabe-kwe (Indigenous woman) of mixed Ojibway-Saulteaux and Celtic ancestry, with kinship ties to Lake St. Martin and Dauphin River First Nations of Treaty 2 in Manitoba. I am a mother and grandmother of two beautiful grandchildren. I am currently a medical anthropologist and former**
registered nurse and have held senior leadership positions with the former Aboriginal Nurses Association of Canada and the National Aboriginal Health Organization. I am currently appointed to the Department of Psychiatry and Neuro-Behavioural Sciences and the School of Nursing in the Faculty of Health Science at McMaster University. I am also the inaugural Associate Dean, Indigenous Health for the Faculty. My research interests include health literacy, Indigenous Traditional Knowledge and health/research/education system reform for Indigenous populations. I currently hold a Heart & Stroke Foundation — Canadian Institutes of Health Research — Early Career Chair in Indigenous Women's Heart and Brain Health. I am committed to addressing anti-Indigenous racism and the promotion of Indigenous self-determining approaches in health equity and system reform. I presently reside on the traditional territory of the Chippewa, Odawa, Potawatomi and Delaware, and Oneida Nations.

**Christina Chakanyuka**

*Mahsi.* As a Métis nurse, educator, and (re)searcher, I honour that the source of my situatedness and knowledge that I hold stems from who I am as a person, where I come from, and to whom I am connected. Growing up on Dené, Cree, and Métis homelands in rural-remote Fort Smith, Northwest Territories, I had the privilege of connecting with the land, water, and my Indigenous roots in ways that shaped my sense of belonging as a Métis woman from a young age. My matrilineal roots are with the Villebrun and Gladue families of Thebacha and Athabasca. I hold strong family ties to my mother’s British, Dené, and Cree-Métis relations, as well as my father’s Scottish-Canadian settler relations. I care deeply about affirming the rights of Indigenous Peoples to self-determination in healing and wellness. I am passionate about co-creating culturally secure space, place, and base for Indigenous nurse wellness in community, and I am committed to working collaboratively with others in Indigenist research-activism guided by the core tenants of anti-racism and love. I am currently teaching and completing my PhD in nursing at the University of Victoria on unceded Coast Salish homelands.
When approached to contribute to this book, several Indigenous nurse scholars carefully considered ideas and concepts that would do justice to the topic. Albeit, one chapter encapsulating all that is involved within an Indigenous ethical world view is an impossibility. We spoke about crucial topics of colonization, racism, land acknowledgements, cultural safety, performative policy (meaning policy that is created for the optics without resources or actionable accountability), research ethics, the value and place of storytelling, deficit-based parameters that pathologize Indigenous Peoples’ health, neocolonialism, reconciliation, world views, White dominance within nursing, and nursing history. How are we able to cover all of these critically important pieces in one chapter? Couple this complexity with the fact that there is diversity and fluidity within Indigenous Knowledge, which shifts in response to living and being.

We are at a point where space for an Indigenous voice is suddenly very visible, valuable, and in demand. Very rarely has academia, and specifically nursing, made room for Indigenous experience, knowledge, and inquiry within our profession, despite years of advocacy at the highest level of government. Increasingly, this is both a blessing and a challenge, as there are relatively few Indigenous nurse scholars being called upon to fill this role. Those with a cynical view might suggest that this invitation to Indigenous nurse scholars is a sign of a “woke” academy that seeks to both check the box of Indigenous authorial space and to add to the credibility of authors, editors, and universities. Alternatively, those of us who take a reasoned view sigh in acquiescence that “at last” we are seen and we must answer the call, as is our responsibility. We collectively hold in high esteem all those relationships with our families and communities that have supported us in the positions we hold. Thus, by fulfilling this obligation, we are reminded to add our voice in authentic and self-determining ways.

We make the decision to contribute to this text with thoughtful introspection regarding our own abilities and legitimacy to speak. As we know, in academia, once something is written, it is in the world for re-use, re-interpretation, and misappropriation beyond our control. We are unable to scrutinize future use of our perspectives, but as members of our Indigenous community of nurse
scholars, we rely on the knowledge that our Indigenous peers and communities will authenticate and critique our presentation and representation of Indigenous voices in ways far more reaching than any academic peer review can provide.

Using our nursing voices, we must develop the content in a way that does justice to Indigenous Knowledge, without perpetuating pan-Indigenous stereotypes, all while upholding the highest ethical regard for the ways in which our knowledge and world view is set to paper. We must also be mindful of ancestral voices that have informed our own diverse expression of ethics, our originality, and how we interpret and infuse our perspective on ethics. Drawing on these distinct views, we carry intergenerational teachings and values through orality and Oral Knowledge-sharing traditions. Our Knowledge Holders, our life experience, our communal understanding and our reflective inquiry guide us as we consider what we can offer advanced practice nurses in the pursuit of upholding Indigenous ethical protocols.

In our contribution to this volume, we use circle pedagogy, in which we explore together what nursing ethics means from our own distinction-based First Nations and Métis nurse perspectives. With this distinction-based approach, we acknowledge the rights and lived experience of First Nation, Inuit, and Métis peoples as unique. This approach aligns with the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (United Nations, 2007) in recognizing and upholding the ancestral teachings of traditional laws and languages while living in relationship to the land. With this approach, we are asserting both distinction and inclusivity, as our experience intersects with Indigenous social determinants of health regardless of constitutional definition or geographic location (Government of Canada, 2021).

Our methodology reflects the ways in which our collective voices are heard, while being accountable to our own teachings and teachers. As an ethical foundation, we centre strength-based views that will help us to formulate cultural safety, cultural humility, and cultural security approaches aimed at taking immediate action to eliminate Indigenous-specific racism.

Esteemed Indigenous scholar Cora Weber-Pillwax provides us with an overarching theme to assist us in focusing on ethical action:
Decolonisation as of this moment has no endpoint; years of social interaction between Indigenous people and the multiple and varied groups of people that form the segments of Canadian population society has shown clearly that decolonisation will not be attained through discussion, discourse, or critical theory. Decolonisation is not merely a concept, it evokes and *stimulates earth- and people-shattering consequences* on a daily basis. (Weber-Pillwax, 2021, p. 3, emphasis original)

This quotation reminds us of the quality of daily life for Indigenous Peoples of this land, as well as the impact of continued oppressive social, economic, and health care policies. As nurse leaders, we have the potential to create change. It is our ethical obligation to do so.

Orality as a method/process has served our communities in the passage of knowledge for millennia. Those of us who work in academic spaces have learned to respond to the demands of the written word. We also long for the ability to create sustainable and spiritual-based relationships by listening to our mentors and learning to speak our truth. This opportunity to engage in reflexive conversations on Indigenous nursing ethics has brought us together to affirm our voices and collectively contribute our individual thoughts in supportive and relational ways.

We are taught by our Knowledge Holders that orality, rooted in language, is imperative for learning in the present, taking what is given, and knowing that what we internalize now is what was meant for us today. There is simplicity in letting go of the need to document every word in text as a means of eliminating the collective spirit and the relational experience, which leads to dominance of the written word (Weber-Pillwax, 2001). We are taught that coming together in circle, speaking and sharing takes on a life of its own and reflects a journey that is unique to each person in relation to their own family and community. Our teachers tell us to “put down our tobacco with our intention for the circle process” (Knowledge Holder teachings, personal conversation, B. Downey, 2022), and in doing this we create the ethical space for our deliberations and exploration of our respective realities. Indigenous scholar Cora Weber-Pillwax (2021) invites readers (and we add listeners) to
“enter into the following narratives as a means of decolonizing engagement rather than as a way of critically following a line of argument. In accepting to enter into the world of the narrative and walking the trail as it has been laid out, readers [listeners] become a part of the decolonising experience” (p. 3). In this way, the learning is active. The listener will take in information based on their current positionality and their aspiration to endeavor further.

While the speakers in the video portion of this chapter approach this subject from our distinct intergenerational perspectives and experience, there are common foundational beliefs upon which we all agree. First and foremost, we do not assert ourselves as ethics experts. We acknowledge that we cannot and do not know everything. We are lifelong learners who have experienced various iterations of genocidal policies that contribute to oppressive and marginalizing actions that have impacted our Indigenous existence in Canada, affecting our access to our ancestral languages, rights, and teachings. We speak today building on the genealogy of our knowing, drawing on those many mentors who have lifted and shaped our ability to hear, grow, and understand the obligations of Indigenous ethical relationality. We celebrate this. We come to this conversation knowing that we are all in fluid processes of reclaiming and renewing our ancestral knowledge. Our voices as we speak our languages may not flow as musically as our ancestors’ did, but the act of speaking them reclaims our relationship to that ancestral voice and is a means of decolonizing our own minds and hearts.

The source of Indigenous nursing ethics, and all Indigenous ethics, is relationship. It serves to bind and create pathways for knowledge to be transmitted, for people to be seen by each other, and for each of us to work to understand who we are in relation to one another. Willie Ermine (Ermine et al., 2004) speaks of the concept of creating an ethical space, which supports the bridging of distance between Indigenous and non-Indigenous cultural divides in a way that honours unique community experience and knowledges.

The idea of two spheres of knowledge, two cultures, each distinct from one another in multiple forms, needs to be envisioned since the distance also inspires an abstract, nebulous space of possibility. The in-between space, relative
to cultures, is created by the recognition of the separate realities of histories, knowledge traditions, values, interests, and social, economic, and political imperatives.

As a process, the fundamental requirements of the ethical space include an affirmation of its existence. The ethical space cannot exist without this affirmation. The affirmation of the space indicates that there is an acceptance of a cultural divide and a direct statement of cultural jurisdictions at play. The ethical space also requires dialogue about intentions, values, and assumptions of the entities towards the research process. The dialogue leads to an agreement to interact across the cultural divide. (pp. 20–21)

This speaks to the work that must be done to create visibility of one’s own positionality and one’s relationship to Indigenous communities by acknowledging what one may know and not know. Work must be done by settler/newcomers who wish to engage in ethical ways with Indigenous communities.

The speakers in the video portion of this chapter each come to this core tenet of relationship with perspectives that reflect our current areas of contemplation, inquiry, and positionality. The historic and contemporary legislated policies in this country have indelibly affected the relationship between settler Canadians, newcomer Canadians, and Indigenous Peoples. In our respective lanes of work, life, and family connection, we speak to Indigenous ethics with humility, knowing that our words represent what we want to say at this moment in time.

Leanne Poitras Kelly is motivated by the experience of teaching undergraduate nurses and engaging with the public on identifying their invisible relationship with Indigenous Peoples. Naming and claiming one’s own relationship is essential to move forward in an ethical way. There has always been a relationship among peoples of the land. Living in Canada means that we all live under the legislation and agreements made by past and present governments. Land allocations, geographical renaming, and access to resources shape the way we understand the world we inhabit. Understanding this means we move forward with insight and knowledge as to our own role in supporting or disrupting oppressive systems.
Bernice Downey builds on relationship work by articulating the critical importance of creating “ethical space” (Ermine et al., 2004) and recognizing “epistemic injustice”\(^2\) which must be addressed. Drawing attention to the *United Nations Declaration on the Rights of Indigenous Peoples* (United Nations, 2007), and the Truth and Reconciliation Commission’s (TRC) multiple reports (TRC, n.d.-a), (TRC, n.d.-b) and calls to action (TRC, 2015) points the way for the learner to engage in structured and sanctioned processes that seek to undo the oppressive injustices of the past.

Lisa Perley-Dutcher asserts her position as a language warrior when she speaks about the interconnection and essential relationship between language, land, and identity. Her own language renewal journey illustrates the active process of being Indigenous and the foundations of healing. The interruption by colonization has shifted focus from collectivism to individualism, which is proving problematic as our societies recognize that strength lies in supportive relationships that go beyond professional interactions.

Mona Lisa Bourque Bearskin lifts up the teachings of love and belonging, which are embedded in the languages of the Cree People and the lands from which they originate. Recognizing that the spirit of being is in constant relation with land, water, and air helps us enact the ethical responsibilities that we all hold to each other. This is based on Kétéskwēw’s (Madeleine Dion Stout) original instructions described in the following four key terms: *tânisi* ᓂᓱᓯ [hello how is your being], *tawâw* ᓂᐦᑦ [there is room for everyone], *tapwew* ᓂᐯᐦ [speaking our truth] and *tipi* - ᓂᐱ [equal opportunities and equal outcomes] (Dion Stout, 2012; M. L. Bourque Bearskin, personal communication, 2010). For nurses who strive for *nahi* [fairness and justice], these teachings illustrate pillars of ethical actions that will form the basis for moving forward in a relationship of wellness that lies within our rights, language, and identity.

As you watch and listen to the video accompanying this chapter, reflect on the diverse ways of managing and respecting knowledge within oral cultures. Think about the use of language and relationship with your own knowledge holders, and your own historical and contemporary relationship with Indigenous Peoples. This reflection is a teaching. Indigenous Knowledges are created by the personal and practical experiences of our lives; they are created by
humour, humility, tolerance, observation, listening, speaking, praying, and sometimes by just sitting quietly. Knowledge comes to us in many ways, and the focus on literacy and the written text has the potential to rob us of this holistic perspective of our culture and our ethics. Speaking and listening is an active process. We are told that decolonization will not occur through discourse alone. The ethical path forward is action. Take what you have heard and build towards change.

**Video Circle Format**

Our decision to use a video circle format to add content to this text was made intentionally and thoughtfully, and was fully supported by the editors. Asserting our voices as Indigenous nurse/scholars involves asserting our own world views as valid and contributory to the canon of accepted academic resources. Each of us brings along the teachings and support that we have received through our lifetime of learning. This process of personal and professional narrative through orality and relationship demonstrates our trust in each other and the deep respect we have in sitting together to share what we have learned. We consciously enter into this circle to assert, as stated by Weber-Pillwax (2021), “a more general acceptance of theoretical or conceptual frames that underpin complexities that lie embedded deeply within Indigenous epistemologies and ontologies” (p. 6). The notion of orality as knowledge transmission is confirmed in the lived experience of Indigenous Peoples for generations. Shared narratives and stories of our lives and lessons is the conduit for all aspects of knowledge generation, such as acquisition, validation, sustainability, and protection (Weber-Pillwax, 2021). The use of circle in this circumstance models the understanding of knowing when it is a time to listen and when it is a time to speak. The video conversation accompanying this chapter consists of three “rounds,” in which each participant responds in turn to the questions posed below.
Round One: Introduction and Personal Positionality

Stating one's positionality involves developing a sense of who we are and what we each represent within an interaction. It is a layered declaration that demonstrates one's commitment to disrupt tacit beliefs and shows insight into one's own involvement in oppressive systems. Our statements of positionality provide the listener/reader with insight into each of our backgrounds, our communities of origin, our pathways to discovery, and our location within settler society. It is our hope that by role-modelling active transparency, we encourage others to do the same.

Round Two: “What Does Indigenous Ethics Mean to Me?”

Each of us comes from different arenas of nursing practice and carries the life experience of being an Indigenous nurse/scholar within the social constructs of dominant society, while asserting our right to Indigenous Knowledge, experience, and legitimacy. Our conversations leading to the video recording accompanying this chapter have positioned us each to reflect on what we have come to know and what we carry with us as guideposts. In this video recording, we highlight a small portion of the very real journey we have all undertaken to live our ethical world views.

Round Three: A Final Round of Take-Home Thoughts

Our closing round provides one last opportunity to briefly summarize, for the reader/listener, what they need to know about Indigenous relational ethics. This round forms the basis for future engagement and action by advanced practice nurses and nurse leaders.

Additional Resources for Readers

This chapter includes extra features not found in any other chapters of this textbook. Below, you will find a Reference section containing the works cited above, supplemental resources for learning more about Indigenous issues and reconciliation, and links to the profiles...
of the video participants, as well as links to the participants’ research and language work.

A major part of this chapter is the Circle video, with the three rounds of discussion as described above. Readers can view the video here: Kelly, L., Bourque Bearskin, M. L., Downey, B., Perley-Dutcher, L., & Chakanyuka, C. (2023). Circle video. [Video]. In R. Starzomski, J. L. Storch, & P. Rodney (Eds.), Toward a moral horizon: Nursing ethics for leadership and practice (3rd. ed.). University of Victoria Libraries. https://hdl.handle.net/1828/14970. A transcript of the video is included with this chapter.

Endnotes

1 According to an article in The Canadian Encyclopedia (Logan, 2021), “The term road allowance originates from the designated space that is measured between a paved or unpaved road and the boundary of where a section of private, municipal, provincial, railway or Crown land is marked.” From the late 1800s to the mid- to late 1900s, Métis people often formed communities on these lands because they were dispossessed or relocated from their homelands.

2 “Epistemic injustice refers to those forms of unfair treatment that relate to issues of knowledge, understanding, and participation in communicative practices. These issues include a wide range of topics concerning wrongful treatment and unjust structures in meaning-making and knowledge producing practices, such as the following: exclusion and silencing; invisibility and inaudibility (or distorted presence or representation); having diminished status or standing in communicative practices; unfair differentials in authority and/or epistemic agency; being unfairly distrusted; receiving no or minimal uptake; being coopted or instrumentalized; being marginalized as a result of dysfunctional dynamics; etc.” (Kidd et al., 2017, p. 1)

References


**Transcript for Circle video**

*Editors’ notes: Places where Indigenous language is spoken are indicated in square brackets. Words from Indigenous languages, when written out, are italicized. Cree words are not capitalized. A few ceremonial gestures are described within square brackets.*


**Opening Section**

**CHRISTINA CHAKANYUKA:** Let’s begin. So, just a big welcome, everyone here today. Lisa, you’ll open in a good way for us as we come together with the intention to share stories and knowledge and ideas. I’ll just pass to you to begin.

**LISA PERLEY-DUTCHER:** [Wolastoqey words. Introduces herself.]

[Shows a short braid of sweetgrass.] Time to smudge.

[Wolastoqey]
Bernice and Leanne, they’re going to do smudge, they’re going to carry on the smudge because I’m in a place where I can’t carry the smoke, so they will carry the smoke. And we’ll all do the prayers.

[Wolastoqey]
[Touches the top of her head.]
[All of the circle members are now visible on the video.]
First smudge your head so that you may take good care of your thoughts.

[Runs her hand in front of her eyes.] Your eyes well too so that you may see all the beauty of the Earth.

[Leanne and Christina touch their eyes; from then on Leanne, Christina, and Mona Lisa keep their eyes down and closed most of the time. Bernice waves a feather gently.]

[Lisa touches her ears.] Smudge your ears well too so that you can hear the great Mother’s words and give thanks.
[Touches her nose.] Smudge your nose so that you can smell all the medicines around you and give thanks.

[Touches her mouth.] Your mouth as well, smudge it well, so that you can honour your language and give thanks.

[Touches her chest over her heart.] Smudge also your heart so that you may honour the love in your life.

[Now Lisa only is visible. She rubs her hands together.] Smudge your hands well, so that you may care for everything on the Earth and then give thanks.

Smudge your legs well too, so that you may walk the Red Road and give thanks.

[She moves her hands down from her face over her upper body.] Smudge well the front of your body so that you can remember the ones who went before you, and give thanks.

[She moves her hands, one at a time, behind her head.] Smudge well your back of your body so that you can remember the ones who are yet to come. Give thanks.

[Once again all members of the circle are visible. The smoke is visible in Bernice’s picture.]

[Lisa shows the sweetgrass briefly.]

I’m just going to sing a welcome song, very short welcome song, for those who are joining our circle today. [Lisa brings out her drum.] It’s important to do the welcoming, take the time to welcome our ancestors into this space with us in this circle. And this is a song of doing that.

[Song in Wolastoqey with drumming.]

[All members of the circle are briefly visible. We see the feathers that Mona Lisa and Leanne are holding.]

MONA LISA BOURQUE BEARSKIN: Thank you, beautiful.

Round One: Introductions

LISA: Welcome. [Wolastoqey] So, my name is Lisa Perley-Dutcher and I’m from the Wolastoqey People here in Wolastoqey territory, also known as New Brunswick. I am living in what’s called Eqpahak (where the tide stops coming in), which is the
Fredericton area, and I am from the Crow Clan, and I’ve been working as a nurse for about 30 years, retired now. A lot of my practice has been around mental health, community health home care, education in nursing. And, you know, volunteering and trying to motivate our young Aboriginal population to take up the practice of health care and to work toward the betterment of our people’s well-being.

Currently, I’m working as a language warrior. And my focus right now is on starting a Wolastoqey, land-based immersion program called Kehkimin.

And so, my focus is there because I believe that’s where healing begins, is at the core of who we are, as the core of who we are is language. And I think that’s a good place for us to start so I believe that, you know, my language was stolen from me and I and I’m reclaiming that back and this is my healing. And so I can give that back to my own people and work in solidarity with them in reclaiming our language. [Wolastoqey.]

**BERNICE DOWNEY:** [Nakawēmowin – Saulteaux] Boozhoo! Minogiizhigad. Bernice Downey, Nigan ekwe, Ndishneekaz. Greetings, good morning. My name is Bernice Downey. I have also been given a name of Head Woman. I’m an Ojibway Saulteaux woman. My family ties are with Lake St. Martin First Nations in the Treaty 2 area of Manitoba where my mother was born. I come from the waters of Kakeganka-Evelyn Sinclair Desjarlais, who came from the waters of Caroline Sinclair, who came from the waters of Elizabeth Beardy. I’m a nindaanis (daughter), a Hini-maama (mother), a Nokomis (grandmother), and a Shugo (Aunty).

The community lived experience is an urban one. I’ve lived in Ontario most of my life. I’m a proud Indigenous woman and my culture is important to me. I do not have a clan. I enjoy learning our language. My mother chose not to teach her children on the language even though she was a fluent speaker, because she was fearful that we would be discriminated against. I have participated in many traditional ceremonies. I also have Celtic settler ancestral roots from County Down, Ireland, a culture I know less about, but I’m also proud of. I’m presently
living and working on a traditional territory of the Chippewa Odawa Potawatomi, and Delaware and Oneida Nations.

I’m a medical anthropologist and Assistant Professor in the School of Nursing and in the Department of Psychiatry, and a long-time clinical nurse. I’m also the inaugural Associate Dean, Indigenous Health in the Faculty of Health Science at McMaster University. I have been a strategic lead for the development of the *Mino Bimaadiziwin Mishkiki aapjishnik Gamik – Tsi nő:we ayakonniyóhake tāhnon aonsayakota’karitehake*, also known as the Indigenous Health Learning Lodge. *Kichi gaygoomah kowabundiu*. It’s great that we see each other here today.

**MONA LISA:** *tân’si nitôtèmtuk*, Mona Lisa Bourque Bearskin *nit’siy’hkâson Amiskosâkahikan nêhiyaw peyakôskân, ostèsimâwoyasiwêwin nikotwâsik* Beaver Lake Cree Nation, Treaty 6. I was born into, I identify with my matrilineal side. My grandmother was Marianne Bearskin, born on the land, traditional descendant of Treaty 6 signatories in Beaver Lake. I currently am living on the traditional and unceded territories of *tk’emlúps te secwèpemc* and I have been, I often say, born into nursing and I have born two of my girls into nursing. And I am Associate Professor at Thompson River University and currently hold BC Indigenous Health Nursing Research Chair, and I am grateful and privileged to be working with the diverse group of First Nations, Inuit, and Métis nurses here in British Columbia.

And just want to honour my fellow sisters here, Bernice and Lisa and Leanne and Christina, for the work that you do and have done for generations, well, decades, I’ll say, when we began our early nursing days with the Canadian Indigenous Nursing Association, and so bringing that work forward still, you know, four decades later is a very important mission and service that we all give our whole essence of who we are to Indigenous health nursing. *aiy aiy*. [She holds up a feather.]

**LEANNE KELLY:** My turn. *Tawnshi kiya*, Leanne Poitras Kelly *dishnikashon*. So as it states in my bio, I am from Saskatchewan originally. My family ancestry is from the Road
Allowance community of Katepwa in the Qu’appelle Valley on my mother’s side, and Turtle Mountain, North Dakota on my father’s side. I’m a mom of two sons, and I’m married to an Irishman, which has granted me access to White spaces and economic privilege.

I currently reside on Coast Salish territory of Vancouver Island in a town called Ladysmith, and I own a home on the unceded and occupied lands of the Stz’uminus First Nation. I’ve been a nurse for 33 years and my nursing work has always been in First Nations communities in Saskatchewan and in BC.

I was not raised in my cultural community, but in small farming towns in the prairies as my dad worked for the CN railway and so we relocated to where the work was. My experience of being Métis-Cree has been one full of dichotomies. Being visibly Indigenous, in a white farming community in the 70s, created a real landscape of trying to fit in, surviving racialized violence, and subjugating a lot of my family teachings to safer and secret spaces. Our parents as well chose not to share the Mishif language with their children.

And so, our connection to our Métis roots really only happened when we would return to our family, our family ancestral home for gatherings. My adult life has been spent reclaiming my Indigenous space, finding my voice, and asserting my right to be seen and valued.

I recently moved into a faculty position at the University of Victoria in the School of Nursing, and I realized I was hired because of my Indigeneity, and I both struggle and celebrate that fact.

I also want to acknowledge that I’m not an expert on ethics, nor do I have any claim to the knowledge that I share. I speak from lived experience and as a beneficiary of many teachers that have supported me. Briefly, I’d like to just acknowledge my parents, the journey that they travelled, my siblings, extended family, of course, all of those teachers, my nursing colleagues that I’ve worked alongside, and in particular the nursing leaders who have literally fed me, including people like Madeleine Dion Stout, Lea Bill, the late Jean Goodwill, all the nurses that are in this space today. My Métis Knowledge Holders, which is Maria
Campbell, Brenda McDougall, Kim Anderson, and all the many Indigenous Knowledge Holders that we have both learned from along the way, and that we continue to seek guidance from, and those, just to mention a few, are people like Cora Weber-Pillwax, Eber Hampton, Shawn Wilson, Kathy Absolon, Margaret/Maggie Kovach and the list goes on.

I just say these names because their writing continues to inspire and inform and propel me and gives me hope. For just naming the space and building it. I’ll leave it there.

CHRISTINA: Mahsi Leanne. Mahsi everyone. My name is Christina Marie MacDonald Chakanyuka.


On my mother’s side of my family, I am connected to the Evans and Barrett families in England. My grandmother immigrated to Canada as a nurse midwife, literally trained at the Florence Nightingale School of Nursing, and came to Canada, met my grandfather, Ernest Villebrun, who was impacted by the Indian Act, which, you know, Bill C-31 was passed and again I don’t think a lot of us nurses know this history. I’m only learning it now. You know, I was born in 1985, Bill C-31 was passed, and my grandfather got his status back because his mom, who was Dené, married a Cree-Métis man. And so, my mom and her siblings, and us, we’ve lived as Métis and I am very proud to be Métis. I identify strongly with that.

But it’s a different sort of ancestral history for each individual person. And that’s something in an introduction that I’d like to share that uniqueness that everybody brings. There’s no such thing as pan-Indigenous.

On my father’s side, Ian MacDonald, and my mom is Marie MacDonald. On my father’s side, his parents Helen and Donald MacDonald were eighth-generation Scottish settlers living in Prince Edward Island on Mi’kmaq territory.

So, I just recognize that right now, I’m on Coast Salish territory, ləkʼəwən territory—it’s not my homeland. I do feel I have an obligation to be present and to be tending to wellness
for myself and for my family while I’m here and being respectful and walking softly on the land here. And if I want to really feel whole, I go home to the north, for sure.

And so yeah, with that, I want to say thank you, everybody, for your introductions, sort of round one to get us started. Lisa, for your opening in such a good way with a prayer and with a song bringing us all together. Leanne, thank you for your vision that you’ve shared, and I want to say also when you were sharing the teachers and acknowledging the Knowledge Holders who have inspired you, I couldn’t help but think yes, those are the names that we hear so much in this circle and in other Indigenous circles when we think about Indigenous Knowledge that has been sort of shared within ethical spaces in academia, recognizing that, you know, it’s like language is living. So is this, this knowledge, so is our ancestry, so is the matrilineal ways of knowing, and so I honour that the women in this room here, Mona Lisa Bourque Bearskin is sort of an academic auntie of mine, Bernice Downey and Lisa Dutcher as well. And Leanne, a real wonderful friend, and sister scholar, and I’m just thankful to be here and I’m just here in the role of timekeeper and to introduce sort of what we’re doing today.

**Transition/Round Two**

**CHRISTINA:** I just wanted to start off with a quote by esteemed Indigenous scholar Cora Weber-Pillwax, providing an overarching theme to assist us in focusing on ethical actions. She says, “decolonization will not be attained through discussion discourse or critical theory. Decolonization is not merely a concept it evokes and stimulates Earth and people shattering consequences on a daily basis.”

That’s Weber-Pillwax (2021) page three and Leanne, I just want to say you and Lisa, both of you, have shared Cora’s teachings with me and I see it as sort of a matrilineal passing down of inspiration as well.

And so, we’re going to be, instead of writing this chapter, having the time to be practicing orality, going around in circle.
We have three rounds. The first round of circle, we’ve already completed, the introductions. So, our first [editors’ note: Christina meant to say “next”] round will be “What does Indigenous ethics mean to me?” And each of us will take a moment to share some thoughts and insights based on what we’ve brought.

Round Two will be reflections and responses, and Round Three will be a final round of take-home thoughts. And so, with that, I’m happy to pass along “What does Indigenous ethics mean to me?” and I think we are planning to start with Leanne.

**LEANNE:** Okay, so, as I mentioned in my opening, I never want to claim that I’m an expert on anything. And so, I guess I just want to share a little bit of something I’ve learned, and I think it probably just builds off the first round that we’ve had. I wanted to draw attention to the listener to consider what positionality as an ethical foundation might mean to you.

You’ve heard all of us introduce ourselves in ways that provide a location. It tells you who we are. It tells you what we bring to this conversation. And I think that learning this skill to interrogate yourself is an important first step. It’s, I guess it’s when you think about Indigenous relational ethics, and wondering, okay, what do I need to do?

First stop is who are you coming to this discussion? It involves interrogating and reflecting on your own relationships to the land where you live, making what might be invisible to you become visible.

So, for people like me, an Indigenous person, not living on my own homelands, self-location is very important in terms of being ethical and accountable. I have to acknowledge that I’m a guest on someone else’s land, and that I cannot speak on behalf of the people of this land, nor can I claim space that doesn’t belong to me. And this is an important, important consideration, because we were migrants, we move, right, we relocate, we travel.

And so, there’s protocols around entering into another territory. There’s consideration that needs to be given. We need to know what kind of relationship we hope to have with the people who are there. And so, that involves us doing some
work. Who are the people that we are becoming neighbours with that we are going to have relationship with. And so, for me, being a Métis-Cree nurse from Saskatchewan, moving to Coast Salish territory, it’s my duty and my responsibility, and it’s my ethical work to uncover what this means. And especially now as I inhabit a faculty role on a territory, not of my own. There’s always some tension or some complexity that exists there. And so, this tension of knowing that I’m on someone else’s land, I am taking up Indigenous space that potentially could be taken by someone who is local, makes me very mindful of the responsibility that I have, to be transparent, to be reminded to walk softly, and to engage with the communities of this land in a way that elevates their experience and their presence.

And so, for non-Indigenous people, this holds true as well. And I would just say, to think about the journey to understand your own relationship with the land you’re on. You know, many of my students who are settlers, non-Indigenous new Canadians say, well, I know nothing about Indigenous history or culture, I, you know, had nothing to do with residential school. And so, the work really is to interrogate these statements. Why is this so? Why do you not know anything? What has interfered?

It’s a myth that there isn’t a relationship with Indigenous Peoples. And this myth has been created and narrated by mainstream societal forces that want to maintain status quo, and to keep Indigenous communities separate. We live on these lands as beneficiaries of a colonial system, and so interrogating your own space and seeing how you have benefited. I mentioned earlier that I own a home in Ladysmith, and this is not necessarily a possibility for people who are born and raised in that territory.

And so, I know I’ve been a beneficiary of these systems and understanding how that has come to be and working to find ways that we can get equity in to action. It’s an ethical responsibility to interrogate your own position, self-location, uncover and discover the relationship, asking yourself, what is your ancestry? What is your family trajectory in relation to the
Indigenous people on the land that you live alongside?
These communities are not invisible. Interrogating your position is an opportunity to do this work.

CHRISTINA: Thank you so much Leanne, we’ll pass to Bernice now.

BERNICE: Miigwetch for this opportunity to contribute to the collective understandings regarding ethics in an Indigenous context. While I acknowledge I am not an expert in the academic field of ethics, I hold up what I have learned and the wisdom I hold from my lived experience and that of my mothers, aunties, friends, and colleagues.

My pathway from a long nursing career to the study of medical anthropology was not an abandonment of nursing, rather a choice of resistance to delve deeply into questions and inquiry and ethics regarding Indigenous Knowledge and health literacy, to hopefully inform biomedical science-oriented programs. So my career and experience has really been about questioning how we do things in health for Indigenous Peoples and how we need to do them better. So, colonization has negatively impacted how we live and draw on our cultural ways as an expression of ourselves and our connection to the world around us. This can be viewed as epistemic injustice, and I’ll come back to this concept in a moment. However, as mentioned in the introductory comments, we’re at a point in time where place and space for an Indigenous voice is suddenly very visible, valuable, and in demand. So, it’s important to note that Indigenous voices all over the globe have been intentionally and pragmatically voicing their realities, aspirations, and self-determining solutions to anti-Indigenous oppression in all spheres of our lives. For example, at the international level, Indigenous peoples gathered for over 30 years to inform and develop the document known as UNDRIP, or the United Nations Declaration on the Rights of Indigenous Peoples. Similarly, at the national level, First Nations, Inuit, and Métis Peoples have given voice to their lived experiences and calls to action through processes such as the 2015 Truth and Reconciliation Commission of
Canada.

They have called for an ethical space. Willie Ermine discusses the concept of ethical space and action and describes how he adapted this concept in response to his experience of frustration within the academy. He needed to talk about this area between knowledge systems and what was happening cross-culturally, how he experienced his own community, his own people, and his knowledge that didn’t jive or fit with dominant Western systems. And he describes this analogy as our cultural (my term) slates being wiped clean and being recreated with dominant ideas. So, he argues that an ethical space can create ideas of dialogue where we can take control of our humanity again, our visioning, our conversations, how we construct our world, our societies that are based on our humanness, not prescriptions from institutions or systems that try to run our lives.

So, the concept of epistemic injustice refers to those forms of unfair treatment that relate to issues of knowledge, understanding, and participation in communicative practices. These issues include topics such as wrongful treatment and unjust structures in meaning-making and knowledge-producing practices such as exclusion and silencing, or unfair differentials and authority or epistemic agency.

So Indigenous Peoples have been making the case to take down the systemic curtains and UNDRIP affirms that we are organizing ourselves for political, economic, social, and cultural enhancement, in order to bring an end to all forms of discrimination and oppression where they occur. This fundamental importance of the right to self-determination has been affirmed in multiple international instruments, and UNDRIP recognizes the urgent need to respect and promote our inherent rights as Indigenous Peoples that derive from our political, economic, social structures, and from our cultures, spiritual traditions, histories, and philosophies. So, when we link this to Indigenous ethics, that are defined as moral principles that govern a person’s behaviour or the conducting of an activity, Indigenous thought leaders, philosophers, and academics have articulated understandings of Indigenous
ethics, most notably in the research context. These concepts are now embedded in Indigenous-led research reform literature and have formed the systemic change we see now within the three major research funding entities. Diverse groups of Indigenous Peoples can align ethical concepts with their own values of honour, trust, honesty, and humility. And these values reflect a commitment to the collective, and are described as embodying a respectful relationship with the land. I don’t recall my elders using the term ethics, but I do recall references to doing the right thing, living in a good way and have over many years. This has guided my own moral compass. And finally, our knowledge can be characterized as bundles that are in flux, knowledge that’s passed on over generations through oral traditions carried by Elders and storytellers. This circle process [makes a quick motion indicating a circle with her hand] that we are now in is an attempt to make meaning in a collective way. And it’s an example of how we continue a cultural method or way of life, sharing our stories, picking up the bundle to add our own truth to it, and in this way, the circle takes on a life of its own language. 

Christina: Beautiful, thank you so much, Bernice.

Let’s finish this round. We’ve got two more folks left. Lisa Dutcher.

Lisa: Woliwon (thank you) Bernice, for your words of wisdom and your inspiration today and for over the years.

You know, I really am so honoured to be part of this circle of Knowledge Keepers. When I was asked to reflect upon what ethics in nursing would mean to me, I had to go back to my language and think about that because I’m so into my language right now [makes hand gestures for emphasis] and trying to bring meaning to my own life and reflecting back on perhaps my practice as a nurse, and what—how did I get—how did I practice ethics in my, in my profession. I looked back and I spoke to Elders and looked at some resources and stuff and, and we have a word that kind of reflects back to this concept [more hand gestures for emphasis]. It’s not an exact English
translation, but it’s how we described somebody who lives well, and has a principled life—Woli-pomawsu. So Woli-pomawsu is somebody who has a principled life. This requires action again. It’s not something that’s a stagnant process. It’s something that is always in motion. And it’s a verb-based language and this is critical because in Indigenous epistemology or in our worldview, we definitely see things as action-oriented and words are part of it, but also there has to be action behind those words. And that’s always, I think that’s pretty consistent throughout most of our various Indigenous cultures.

One of the phrases that really stuck with me growing up was this concept of wicuketultiq. I was always taught to help those who were in need of it. It was the core of who I was, what I was always taught, and I was taught it not by being told to do it, but I was told, okay, now it’s time to go help this Elder, now you have to go help this Elder, you have to go get groceries for her, you have to go clean her house. So, my grandmother was teaching me, without telling me, about my responsibility to community, my responsibility to our Elders.

And this was really the foundation of my nursing career, because this is why I actually went into nursing because I had that caring, and maybe she saw that in me was that caring ability to move it into action. And you know, this basic teaching, of caring for others in the teachings that she gave me really, it covers so much, it covers all the sacred, you know, teachings, seven sacred teachings, and I think, you know, if we were to follow our basics, you know, seven teachings of respect, caring, sharing, you know, responsibility and, and respect and empathy and all of that (I can’t remember all of them, right now), but I mean, that you get the idea of that, you know, these are the foundation of our relations of how we respond to one another, right?

So, you know, I went into nursing with this foundation already. So, to me, I think it made me a good nurse in that, you know, and I’ve always had people come up to me and say, “You were the best nurse I had!” [Laughs.] So, I often wonder like why, why, why was that? Like why, why am I different?
But it’s that foundation from my grandmother. And I think she really embedded that within me to be caring, and that’s the healing part of nursing. And if you take that out it’s not the same and there’s a word in our language, *nuci-kikehtahsit/nutsihpiluw*, which means a healer, and that’s how they refer to us. The nurses and doctors are the same term because that’s how our people see us. We’re the healers of modern day. Right? So, because we know how to bring that, that carrying, that responsibility.

There’s been an interruption in our cultural ethics or our way of being a principled life because this whole individualism versus collectivism has really disrupted that—those teachings because we’ve become so focused on self that, you know, really our responsibilities have kind of been disrupted in that way. And really, especially even today, it’s even more important because it’s a matter of survival—was a matter of survival *then*, it’s *still* a matter of survival for us, as the human race is we have to get back to collectivism. We have to be able to look out for one another. And that drives ethics, that drives a principled life, you know, and like I say, it’s what grounded me in being who I am, and my own experiences as going into nursing and learning the profession from a Western point of view, I often felt conflicted, because, you know, I wanted to establish meaningful relationships with clients, but I was often told, Oh, no, you can’t establish those kinds of like close relationships with your clients because it’s not professional. Or you can’t, you know, you can’t bring those stories to the table because you can’t back them up with the literature; and so your knowledge is not enough, your Indigenous knowledge isn’t enough. So, these are the kind of stories that have been told to us in in our profession, and I think I believe that it’s kind of come to an end, that that kind of way of thinking is coming to an end and you know, we are being listened to now more than ever and I think this is, you know, something that, you know, if our allies want to be true allies, you know, I think that role of advocacy of, you know, allowing us to step forward to bring our teachings forward in a good way will not only benefit our own people but will benefit the entire world. I believe that and I think that you
know if we were given space to bring these teachings forward it would help to, like really complete the circle [makes a circling motion with her hand] of like, where we need to be. I mean, my Elder just told me this the other day, she said, you know, my mother used to say, my mother used to say it over and over again, is there’s going to be a day when it’s our day.

This is our day. And this is the time when we need to speak these truths. And we are hoping that you are listening and that, you know, not only will you listen, but we hope that you will hear what we are saying and that somehow you will find a way to incorporate these true ways of caring and teaching, which will guide your ethical behaviour [we see that Lisa is holding the sweetgrass again]. You will do the right thing when you’re come from that good place in your heart [points to her heart]. You will always do the right thing, because you’re listening. [Wolastoqey words as she lifts the sweetgrass.]

**CHRISTINA:** Aah, this is beautiful. It’s such a privilege to be here with your wise ones. I remember Madeleine Dion Stout once saying, you know, we were nurses too, and a family member had told her that, pre-contact, right? We were nurses too, it didn’t start with Florence.

Lisa, I’m really happy to pass to you, Mona, Mona Lisa, and for you to share your thoughts and your—what does ethics mean to me.

**MONA LISA:** sākihitowin. [To love one another.]

kisâkihitin. [“You are loved by me.”]

And with that I want to give back to each one of you women here today that enormous amount of love that is my ethos for being. It’s something I’ve had to come to learn—how to love—as a result of epistemic injustices that Bernice articulated very nicely for us. And also the support and the guidance in Leanne’s words on the importance of interrogating self.

And my colleague, Lisa, really bringing full force the importance of the individual in the collective, and it’s the collective that we’re here to serve. And that’s the ethos of practice and grounding our work in our own language, and our own knowl-
edge systems that are our own way of being, and acknowledging those trailblazers that have come before us—kikatikameskew [Lea Bill], kētēskwew [Madeleine Dion Stout], gilgaletlilok [Evelyn Voyegeur] and maskihkîwiskwêw [Alice Reid]. My four key knowledge holders that I’ve come to learn, really, the essence of my own Cree ontology and how coming to reconcile how nursing facilitated that separation of my identity of who I was as a nurse, as a human being, and taking the space in places of love that we can now exchange and help transform the future for those who have yet to come behind us.

And so, one of the key principles of Indigenous ethics that I think about, it’s always in constant relation. It’s constant relation with the land on where we all live, and we benefit from. It’s that constant relation with the air we all breathe. It’s that constant relationship with the water, the most commodified natural resource across the globe. And we’re losing and we’re draining Mother Earth and we see that happening today, in the global issues that we’re facing.

Mother Earth is suffering from an infection, and you can see it from the natural disasters across every corner of this globe, in the country and the world and the human devastation that we’re seeing with human kindness. And so, as nurses, how do we speak up and how do we create the space for something I’ve come to know, mâmaw ohkamâtowin (working together to help each other). How do we help each other? How do we help move each other in a good way?

And a good way doesn’t mean that we don’t have these difficult conversations, that we don’t give sharp feedback. And that we hope that it’s taken. As you mentioned, Lisa, with ears wide open. We have—it is time now. We are in that time. You know, I think about Jean Goodwill, you know, in her advocacy back in the early 70s. You know, the leadership she provided, the leadership Indigenous nurses for back then, you know, four decades ago, the first adviser to the Minister of Health in the country? And we have, we’ve lost some of that and we’re now starting to gain some footing. So Indigenous ethics, to me, is honouring that sacred space, and it’s honouring our language and four key terms that I just want to be remindful of
that I’m always remindful that I bring into my nursing: tân'isi, tawâw, tapwew, tipi were gifted to me in my teachings from Madeleine. And when we talk about tân'isi it means it’s more than “hello.” When we’re talking and we’re introducing that concept, it’s actually honouring the spirit of another person. And that’s what’s missing in nursing. We’ve done a really good job of removing the spirit. We have a sickness of separation. And so that brings the significance of the next word, tawâw, there’s room for everybody here.

This is that distinction base. We need to reclaim our own identity; we need to reclaim our own positionality; we need to move beyond those impacts of those legislated identities. We need to honour UNDRIP; we need to honour the fact that health is a human right, it has not been afforded to First Nations, Inuit Métis, people in Canada. Which brings me to the next word. tapwew. Which means to speak our truth.

And this is time I think that’s the time we are at reconciliation. We are speaking our truth. And debate is about equal opportunity for equal outcomes. This is not about equality across the board. We need to look at those inequities and outcomes. Enormous amounts of dollars in funding into research in nursing education has continued over the last five decades and we continue to see the same issues.

And so in nursing, I draw on Levanis, a philosopher, who really talks about ethical responsibilities when we look in the face of the other, really spoke to me, when I was on the land and during one of my ceremonies, was looking for that face and I looked up through the trees and I saw this beautiful image of the face carved in the mountain. The image of a face looking up at mother sky, and it was just like a huge sign to me that we are living on the backs of Mother Earth and we do benefit. And if we really, truly look in the face of Mother Earth and the patients when we go to their bedside, that’s that ethical responsibility we have. Well your mind talks about that, right?—that relational space and that energy transformation that when we come into someone else’s space, in their hospital room at their bedside, that we don’t take up too much space. We’re so trained as skilled practitioners, with IVs and catheters
and medications, and we bring that expertise, but what we
don’t, what we need to work a little bit harder is the spirit. That
spirit of nursing care and that service that we have, and I just
want to finish off with when I think about nursing ethics.

One quote by Stan Wilson, you know, and I’ve heard you
guys quote other scholars, for me it was Cora Weber-Pillwax—
first Indigenous woman practitioner to get a faculty position to
bring Indigenous education into a program of study. So, when
I think about Indigenous ethics, both just as a human being
and what I bring to my nursing practice, I’m always reminded
of what Stan shared with me one time, and I quote him here
now. He talks about

I’m walking on the sacred ground. If my ancestors died
here, the remains are in the soil, the remains have
become part of the soil, enriching it in the process. The
grass that grows here would be getting its nourishment
from the soil and from the remains and so my
ancestors are in this grass. My ancestors are in this
water. My ancestors are in the trees, and we share and
breathe life with them every day. (S. Wilson,
Opaskwayak Cree Nation oral communication, May
2009, University of Alberta)

The life of the leaf in the tree in the bird that eats the worm,
and that shows that reciprocal connection to all of life and how
we’re all connected, just through even one breath. And I’m
grateful that I could share this breath and this energy through
this virtual seminar with you all today. aiy aiy. [She lifts her
hands up.]

CHRISTINA: aiy aiy, Lisa. Thank you so much.

Round Three/Closing

CHRISTINA: Well, we’ve got just a few minutes left. And so, we’re
going to do a final just closing round in one minute. One
minute to share what do nurses need to know about Indigenous ethics? We’ll start with you, Leanne.

LEANNE: All right. Okay, one minute or less. I can’t say that I can really capture it all in. But, as you know, we’re all bringing our teachings to the circle.

I’ve been told time and time again by many people from my location, the idea of Wahkohtowin, which is all about relationship, relationship, defining what that is and within that relationship, articulating, what is your obligation. What do you owe? What do you build on and who has taught you these things?

Maria Campbell says to me that nothing will change without waskewiwin, which is movement. You have to take action, move, get that spirit rolling. And to do it right means to identify your obligations once you’ve done the learning.

CHRISTINA: Beautiful. Thank you, Leanne. aiy aiy, Bernice.

BERNICE: Miigwetch, Leanne, miigwetch everyone for your beautiful words and teachings today. I’m just reflecting that the common thread does seem to be language and, you know, the beauty in hearing how we align what we learn from the academic side to what we understand in the language. It’s just a beautiful moment whenever it happens. So, someone who lives well, you know, it gets to the point it reflects who we are, and it reflects how we bring the spirit into nursing, into health care.

And also speaking our own truth that Lisa mentioned, you know, obdawin in Anishinaabe, and my affirmation of paydshiquin, which is a Saulteaux word, meaning to create a constant such as a circle that can be applied to the concept of “completing the circle,” and I wrote about that as the essence of a proposed IND-equity model.

And of course, the circle refers to our diverse cultures. So non-Indigenous nurses can assume the ally role and work alongside Indigenous nurses and other practitioners, including traditional practitioners, so that they can complete the circle in their roles alongside us, and in turn learn to understand what ethics means to us and what that ethical space can be. Miigwetch.
**Christina:** Thank you, Bernice. Lisa.

**Lisa:** I really, to sum it up in one minute is to say, really honour and respect yourself.

Because truly, if you cannot do that for yourself, you cannot do that for other people. And I think that if you go back and you reflect on what is the foundation of your ethics, where do you get your values and your beliefs from? What are those values and beliefs? Are they congruent with the people that you are working with? If they’re different then you need to learn about how they’re different. I really think that’s really because I mean, values and—you know, those come from a cultural perspective.

So, ethics actually comes from a cultural perspective. So, how we define what’s right and wrong, comes from a cultural perspective. So, we need to see it, try to see it for ourselves, from through our own eyes, but also try to see it from the other’s eyes as well. To see what is their truth.

What are they … what constitutes their, their principled life, and, and try to be open to that, and learn. I think, to me, that’s really what, you know, being a healer is about. And your responsibility as a healer requires you to do that.

[Wolastoqey words.]

**Christina:** Beautiful. Mona Lisa, over to you.

**Mona Lisa:** Oh, wow, just so very grateful. Key messages for me, I think, for all nurses and particularly because the space is Indigenous. It’s being able to honour the spirit of Indigenous nursing knowledge, so that we can all reclaim our own nursing bundles in our healing bundles, and that we can continue to be of service in a good way, and that we can whatever we do, the responsibility to bring community with us has to be central to the work moving forward. *aiy aiy.*

And so, with that, my final words of *kisàkihitin,* meaning you are loved more dearly than myself.

And that is the epitome of Indigenous ethics to me that I always uphold everyone else first before myself. *aiy aiy.* [Mona
Lisa brings her hands up. As the camera shows all the circle members, we see Leanne and Lisa bringing their hands up at the same time.]

CHRISTINA: Thank you so much, Lisa.
Additional Resources

References


**Land Acknowledgement Links**


**National Indigenous Cultural Safety Collaborative Learning Series (ICS)**

https://www.icscollaborative.com/home

Description: “This national webinar series provides an opportunity to share knowledge, experiences, and perspectives in support of collective efforts to strengthen Indigenous cultural safety across sectors” (home page, para. 1).

**Declaration on the Rights of Indigenous Peoples Act Action Plan: 2022–2027**


**Video Participants’ Profiles and Resources**

**Leanne Kelly**

University of Victoria Profile:
https://www.uvic.ca/hsd/nursing/people/home/faculty/profiles/kelly.php


**Mona Lisa Bourque Bearskin**

University of Victoria profile: https://www.uvic.ca/hsd/nursing/people/faculty/profiles/bourque-bearskin-lisa.php


**Bernice Downey**

McMaster University Profile: https://nursing.mcmaster.ca/faculty/bio/bernice-downey


**Lisa Perley-Dutcher**


The Language Conservancy. (2020). *Who we are.* The Language Conservancy. https://languageconservancy.ca/who-we-are/

**Christina Chakanyuka**

University of Victoria Profile: https://www.uvic.ca/hsd/nursing/people/home/faculty/profiles/chakanyuka.php

THE WORDS FROM LIASCHENKO AND PETER, two leading North American nurse ethicists, emphasize the significance of the moral challenges that nurses and other health care providers (HCPs) often face as they work to fulfill their professional ethical responsibilities in health care practice. Liaschenko and Peter argue that feminist ethics provide a helpful lens from which to view the work of nurses in context because of the “inextricable relationship between ethics and politics” (p. S18). Our own thinking has also been informed by the work of diverse feminist ethicists, including Baylis, Kenny, and Sherwin.¹
We begin this chapter with insights from Liaschenko and Peter (2016), which serve as a catalyst for us to analyze the means by which advanced practice nurse leaders and other HCPs can navigate ethical challenges, and promote positive ethical practice for individuals, families, and communities. Foundational to such practice is a relational approach, which “demands an explicit focus on the social and political contexts of individuals in its moral deliberations” (Sherwin, 1992, p. 40). By promoting and sustaining this commitment to a relational approach, nurses and other HCPs are enacting their moral agency—that is, engaging in deliberative action to make “self-determining or self-expressive choice” (Taylor et al., 1992, p. 57). However, when nurses and other HCPs are unable to enact their moral agency, they may experience moral distress, which is recognized as arising when they are “unable to act according to their moral judgment” (Rodney, 2017, p. S7).

The concept of moral distress originated with ethicist Andrew Jameton (1984) in his landmark text on nursing ethics. Until that point, distress among nurses had been understood primarily through psychological concepts such as stress and burnout, which, although relevant, were not sufficient to fully describe the moral phenomena that nurses were experiencing. With the introduction of the concept, Jameton added an important ethical dimension to the study of the distress experienced by nurses and other HCPs, which has had significant and longstanding impacts on scholarship in nursing.

In this chapter, we begin by defining moral distress, examining the basic assumptions underpinning the definition, and differentiating it from other related concepts. We then discuss the insights of leading ethical theorists, to explore the moral context of nursing practice and health care delivery. We highlight the importance of the moral reasoning and moral action of nurses and other HCPs—that is, their enactment of their moral agency—as foundational to the prevention of and responses to moral challenges in their practice. We explore situations where nurses and other HCPs experience moral distress because they are unable to enact their moral agency in the often challenging and resource-constrained moral climates where they practice (Austin, 2012; Jameton, 1984, 1993; Musto et al., 2021; Rodney, 2017). We present information about research on
moral distress and the debates about its evolving definitions, pointing to the importance of ongoing work in developing effective interventions to address the issue. Finally, we highlight the importance of moral leadership in fostering ethical clinical practice environments, providing recommendations at individual (micro), organizational (meso), and larger system (macro) levels for advanced practice nurse leaders to improve the moral climate of health care practice environments.

**Differentiating Moral Distress from Overlapping Concepts**

We initially focus on the debates surrounding moral distress and on differentiating moral distress from other closely related concepts such as moral residue and moral injury. Later in the chapter, we move on to tracking the contemporary arguments around broadening the definition of moral distress and weigh in with our own responses.

When Jameton introduced moral distress into the nursing literature, the concept resonated with nurses as a felt experience of something that had thus far not been named. Jameton described a phenomenon he observed as nurses recounted ethical situations that seemed to fit somewhere in-between the categories of moral uncertainty and moral dilemma (Jameton, 1984). As moral distress was a new concept, early researchers studied it, attempting to gain a greater understanding by delineating the parameters of the emotional, physiological, and psychological experience of moral distress, as well as the conditions that caused it (Wilkinson, 1987). Nurse researcher Wilkinson, the first to conduct research on the experience of moral distress, identified that indicators of moral distress have “cognitive, situational, feelings, and action dimensions” (p. 20). Other nurse researchers, including Liaschenko and Peter (2016), and members of our own research team (Varcoe et al., 2003), have also studied the concept of moral distress.

Over time, as research data accumulated, some scholars argued that the term “moral distress” was being used without critical examination of what the concept actually meant. They highlighted some significant concerns about the use of the term moral distress, such as conflating it with psychological distress, burnout, and other
closely related concepts (Hanna, 2004; Lutzen & Kvist, 2012; McCarthy & Deady, 2008).

The overlap of symptoms of moral distress with compassion fatigue, burnout, and vicarious trauma have also contributed to a conflation of concepts. Further, in the literature, overlapping concepts are discussed in the same articles but are not explicitly differentiated from each other. Conflation between moral distress and related concepts has led some researchers to identify what moral distress is *not*, while setting parameters for what it *is* (Varcoe et al., 2012). In Table 6-1, we describe concepts that overlap with moral distress. Our intent with the table is not to try and neatly categorize each concept. Rather, we hope to highlight some of the distinguishing characteristics of each concept to prompt deeper thinking about what HCPs are actually experiencing. It is important to note that HCPs may experience moral distress concurrently with compassion fatigue, burnout, and vicarious trauma.

As provincial and federal governments look to restructure and rebuild the health care workforce, it is imperative that nurse leaders (and other HCPs) distinguish between moral distress, burnout, compassion fatigue, and vicarious trauma. Conflation of these concepts carries at least two obvious risks: (a) failure to differentiate moral distress from burnout, compassion fatigue, and vicarious trauma will lead to overlooking the moral aspects of care in general, and overlooking the moral obligations unique to the professional identity of practitioners; and (b) while some interventions for moral distress, burnout, compassion fatigue, and vicarious trauma at the individual level may overlap at the organizational level, interventions need to be targeted at the specific root causes. For example, fostering moral community has been strongly recommended as a means of addressing moral distress (Epstein et al., 2020; Liaschenko & Peter, 2016; Traudt et al., 2016). If health care organizations fail to institute interventions specific to moral distress, there is a great risk that nurses and other HCPs, who experience moral challenges in practice, and “who feel a strong sense of responsibility to patients and for their own actions” (Wilkinson, 1987, p. 27), will leave their jobs or their professions altogether.
### Concepts Overlapping With Moral Distress

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
<th>Differentiating Concepts</th>
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<tbody>
<tr>
<td><strong>Moral Distress</strong></td>
<td>Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action (Jameton, 1984).</td>
<td>Moral distress brings explicit focus to the experience of an HCP when they feel morally compromised when they fail to live up to the moral obligations of their profession. The experience of moral distress is linked to the health care context and whether having the necessary resources and supports are available to practice according to a professional code of ethics. The experience of moral distress is also connected to the concepts of moral identity and moral community.</td>
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<tr>
<td><strong>Moral Injury</strong></td>
<td>Moral injury is a betrayal of what's right by someone who holds legitimate authority in a high-stakes situation (Shay, 2014).</td>
<td>This definition of moral injury comes from Jonathan Shay, a psychiatrist working with soldiers in the American military. Central to Shay's definition of moral injury is the military’s betrayal of the fiduciary relationship with soldiers. In health care, a fiduciary relationship exists between the health care organization and health care professionals. While there is conceptual overlap between moral injury and moral distress, in the military the experience of organizational betrayal/leadership malpractice leads to the <em>disintegration of character</em> (2011). The key distinction between moral injury and moral distress is the resulting disintegration of character in moral injury.</td>
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<tr>
<td><strong>Moral Residue</strong></td>
<td>Moral residue is that which each of us carries with us from times in our lives when we have seriously compromised ourselves or allowed ourselves to be compromised (Webster &amp; Baylis, 2000).</td>
<td>According to Webster and Baylis, moral distress and moral residue are closely linked. Moral residue involves a form of moral compromise that results from moral failing, a betrayal of fundamental moral principles that weakens one's moral integrity or wholeness. Moral residue irrevocably changes a person “for good” or “for ill” (pp. 224–226); either by helping a person clarify their personal moral boundaries (for good) or by leading to error, becoming a “moral chameleon” (for ill) (p. 224).</td>
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<tr>
<td><strong>Burnout</strong></td>
<td>Burnout is a psychological syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur among individuals who work with other people in some capacity (Maslach et al., 1997).</td>
<td>The experience of burnout is currently understood to result from exposure to chronic organizational stressors such as excessive workload and understaffing. Interventions to address burnout are directed at improving organizational processes and creating a healthy work environment (Kelly, 2020).</td>
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<tr>
<td><strong>Compassion Fatigue</strong></td>
<td>Compassion fatigue is a state of exhaustion and dysfunction—biologically, psychologically, and socially—as a result of prolonged exposure to compassion stress and all that it evokes (Figley, 1995).</td>
<td>Figley identifies compassion fatigue as being a symptom of post-traumatic stress disorder (PTSD) but at a subclinical level (p. 24). Figley’s definition of compassion fatigue centres on symptoms such as emotional and physical exhaustion, apathy, and desensitization to the needs of patients and others (Henson, 2020), which result from exposure to the trauma suffered by others. They refer to compassion fatigue as the “cost of caring.”</td>
</tr>
<tr>
<td><strong>Vicarious Trauma</strong></td>
<td>Vicarious trauma is the transformation in the inner experience of the therapist that comes about as a result of empathetic engagement with clients’ trauma (Pearlman &amp; Saakvitne, 1995).</td>
<td>Pearlman and Saakvitne ground vicarious trauma in constructivist self-development theory, and describe it as a process that occurs over time, resulting in (potentially) permanent changes in a therapist’s/HCP’s identity, worldview, and spirituality. There is an overlap of symptomology between vicarious trauma, burnout, and compassion fatigue; however, the authors look beyond symptoms to focus on the permanent and fundamental changes to therapists’/HCPs’ perspectives resulting from repeated exposure to trauma experienced by others.</td>
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Basic Assumptions Underpinning Moral Distress

Jameton’s (1984) description of moral distress reveals three basic assumptions: (a) nurses have the capacity to make a moral judgment about the rightness or wrongness of a particular action in the context of professional practice; (b) nurses experience institutional (external) constraints; and (c) nurses often do not act on moral decisions because of these constraints. However, as nurse researchers and scholars considered the definition, the ambiguity in each of these assumptions prompted recognition that moral distress lacked conceptual clarity (Varcoe et al., 2012; Wilkinson, 1987). Each of Jameton’s assumptions has been critiqued, the result being a reworked definition offered by scholars and researchers in nursing and other disciplines, or the suggestion to abandon the concept altogether (Johnstone & Hutchinson, 2015). As well, these critiques raise other questions: (a) What exactly was Jameton describing when he identified moral distress—a situation or an experience? (Fourie, 2015; Hanna, 2004; Paley, 2021); (b) What is the nature and location of “constraints”? (Austin et al., 2003; Varcoe et al., 2012); and, importantly, (c) What is the impact of moral distress on patient care? (Wilkinson, 1987). Notwithstanding the critiques and questions, studying the concept of moral distress has opened up emerging possibilities for nurses and diverse HCPs to strengthen ethical practice. For more details about evolving definitions of moral distress, refer to Table 6-2 in the section “Evolving Definitions of Moral Distress.”

As we continue to examine the evolution of the concept, we point to the disciplinary roots of moral distress. It is important to note that the concept of moral distress originated within the discipline of nursing. As such, the assumptions that underpin the definition arose from a specific disciplinary perspective of working in health care. The introduction of the concept heightened awareness of the challenges of moral agency in the presence of structural constraints in nursing. However, the singular disciplinary perspective from nursing has, at times, limited the understanding of moral distress (Musto & Rodney, 2018). For instance, the concept of moral distress has also been critiqued as perpetuating a disciplinary narrative of nurses as “victims,” powerless to be moral agents in the
face of ethical challenges (Johnstone & Hutchinson, 2015; McCarthy & Gastmans, 2015; Paley, 2021). A second critique related to moral distress is that some have interpreted nurses “knowing the right thing to do,” as though nurses have moral certainty about patient interventions. Some nursing scholars have pointed out that (a) a nurse’s determination of the “rightness” of a particular intervention or approach to care cannot, and should not, supersede the decision making of other HCPs, such as physicians; and (b) that making a moral judgment is a complex operation that often occurs outside of conscious awareness and is based on a constellation of factors, including personal beliefs, education, and upbringing (Johnstone & Hutchinson). We agree with Johnstone and Hutchinson that the moral judgments of nurses ought not to take precedence over the moral judgments of other HCPs. However, we question whether the critiques above reflect accurate interpretations of what Jameton meant when he included the idea that nurses “know the right thing to do” in the definition of moral distress. Jameton does not qualify what he meant by “know,” and assuming that nurses or other HCPs are certain in their knowledge would likely be unwise.

Health care researchers have examined how moral distress is experienced differently across professions in order to better understand the necessary and sufficient elements that comprise the experience of moral distress (Crane et al., 2013; Morley et al., 2019). For example, lack of autonomy in practice has been identified as a source of moral distress among nurses; yet, for physicians, autonomous decision making has been identified as a source of moral distress (Crane, et al.). This supports the recognition that although moral distress is experienced across health care disciplines, the root causes are influenced by specific disciplinary foci (Epstein et al., 2019). Overall, nurses experience higher levels of moral distress than HCPs in other disciplines (Dodek et al., 2016) due to their position within a hierarchical health care system, extensive engagement in patient care, and inadequate collaboration with physicians (Peter & Liaschenko, 2004).

Developing and implementing strategies for nurses, as well as other HCPs, to feel supported in the enactment of their moral agency are, therefore, crucial research and practice goals. Over time,
the three editors of this book, together with other colleagues, have had the opportunity to engage in and co-lead research programs focusing on these goals. Throughout our research we learned that purposefully listening to and learning from nurses and others on the front lines of patient care is a prerequisite to addressing the sources of moral distress for nurses and other HCPs. We also learned that thoughtful engagement of nurses and other HCPs in improving the conditions of their work environment can strengthen the sustainability of the health care workforce.

Incorporating an understanding of the experience of moral distress across a range of health care disciplines has pushed examination of the assumptions regarding moral distress to a higher level of abstraction, so that scholars understand it as a violation of the ethical obligations specific to the professional identity of individual HCPs. For example, the definition of moral distress used by Dodek et al. (2016) in their multidisciplinary research is as follows: “Moral distress is the powerlessness, anger, and guilt health care professionals experience when they are unable to practice according to their ethical standards” (p. 179). Implicit in this definition is that HCPs across disciplines experience moral distress when they perceive that their professional codes of ethics are being violated. This focus on professional codes of ethics addresses the critique from some nursing scholars that nurses or other HCPs are presumed to somehow “know” the right course of action. Moral compromise is tied to disciplinary practice, not necessarily to decisions, about the direction of patient care interventions. Increasingly, researchers and scholars are recommending the development of moral communities as a means of fostering professional identity and moral agency, as well as mitigating the experience of moral distress (Epstein et al., 2020; Liaschenko & Peter, 2016).

Nurses as Moral Agents in Constrained Work Environments

Jameton’s (1984) groundbreaking insight was to identify moral distress as “what nurses (or any moral agents) experience when they are constrained from moving from moral choice to moral action—an experience associated with feelings of anger, frustration, guilt,
and powerlessness” (Rodney et al. 2013b, p. 169). Nurses have fundamental ethical obligations to the individuals, families, and communities for whom they provide care. This has meant that the study of nursing ethics—including enactment of nurses’ moral agency in fulfilling their ethical obligations—has become an increasingly relevant field of inquiry. The Canadian Nurses Association (CNA) (2017) has stated “Nursing ethics is concerned with how broad societal issues affect health and well-being. This means that nurses endeavor to maintain an awareness of aspects of social justice that affect the social determinants of health and well-being and to advocate for improvements” (p. 3, emphases in original). Further, based on their professional expertise, nurses are moral agents helping people who are in need of nursing care. Given the significance and complexity of the responsibilities nurses hold, support of nurses as moral agents ought to include attention to the socio-political, historical, and relational contexts in which they work (Rodney et al., 2013a, 2013b).

Several socio-political challenges have contributed to increasingly resource-constrained health care environments that are shaping the ethical context of practice, including moral challenges confronting nurses and other HCPs. These challenges include the application of neoliberal ideologies to social programs such as health care, as well as technological advances that have contributed to the increasing acuity of patient illness and the escalation of chronic illness. At the same time, the ongoing impacts of SARS-CoV-2 on HCPs have exposed deeply fractured health care systems in diverse countries, including Canada (Ness et al., 2021).

Although nurses as moral agents are committed to ethical practice, they, and other HCPs, face significant challenges in their practice. These challenges are exacerbated by neoliberal discourses of scarcity, where it is assumed that there will never be enough resources. This assumption can lead to rationing, the need for greater efficiency in health care services, and ongoing tightening of physical and human resources (Musto et al., 2021), all of which became particularly urgent during the COVID-19 pandemic. Austin (2011) tracked the consequences that could occur as organizations sought greater efficiency through rationalization of services based on corporate values. Importantly, they highlighted an unspoken
shift in values in the moral context of health care—from the patient as a vulnerable person, towards the patient as a consumer—and the impact this shift could have on nurses. Austin stated that nurses often experience a reduced sense of agency because they are constrained by market-driven health care decisions that reduce their ability to provide “safe, compassionate, competent, and ethical care. … [Such experiences] affect the way they perceive themselves as nurses” (p. 165, emphasis in original).

In the home care context, nurses may feel complicit in moral wrongdoing as they work in a resource-constrained program that limits the care they provide (Peter, 2013). For instance, home care nurses may have to allocate their time to a physical wound or dressing instead of providing holistic care that supports patients and their families’ needs and preferences. Providing care at the end of life can also raise particular moral challenges and opportunities for nurses and other HCPs. Nurses provide end-of-life care in various practice contexts, from high acuity through to home care. Regardless of the practice context, the goal is to offer optimal care to patients, their families, and other members of the health care team. This is a goal that requires “a focus on the individual patient’s well-being as a point of reference” (Doherty & Purtilo, 2016, p. 335), which has become increasingly difficult in resource-constrained health care environments.

**Moral Agency, Nursing Practice, and Leadership**

Foundational to all health care professional practice is a mandate to recognize and act on moral obligations to the individuals, families, and communities for whom nurses provide care. Being a nurse, therefore, entails being a moral agent, which Storch (2013) defined as “someone who has the capacity to direct his or her actions to some ethical end—in this case, good outcomes for patients” (p. 10). Traditionally, moral agents have been perceived as independent and rational individuals who made decisions based on self-interest and in isolation from outside influences (Sherwin, 1992). However, scholars in feminist ethics, such as Sherwin, have critiqued this view of moral agency as unrealistic, arguing for a relational perspective of moral agency that acknowledges the socio-political and contextual
influences on moral decision making. Researchers in moral psychology have conducted studies on moral decision making and also offer support for a relational perspective (Milliken, 2018).

In health care leadership, the moral agency of nurses and other HCPs needs to be understood in the current context of health care delivery. The emphasis on containing costs and increasing efficiency has shifted health care environments to places where HCPs are asked to be task-focused. The importance of structuring environments to promote or support the ethical aspects of practice has been overlooked (Austin, 2011). Consequently, an individual nurse or HCP may take up responsibility for the moral aspects of care that are, in fact, beyond the scope of their authority to address (Austin, 2016; Milliken, 2018). Milliken examined the concept of moral agency in light of current research and theory from moral psychology and moral philosophy. In refining our understanding of what it means for a nurse to be a moral agent, Milliken stated that “[r]ather than focusing on the individual nurse, realistic considerations of moral agency must take into account what is possible of an individual in a highly complex system, and must examine what elements of the system and environmental context need changing” (p. 5).

In the Ethics in Practice scenario below, we describe a situation where a nurse experiences moral distress because they are unable to assert their moral agency and fulfill what they perceive as their responsibilities as a nurse, within a system characterized by staffing deficits, as well as poor leadership and teamwork.
Chapter 6: Nurses and Health Care Providers as Moral Agents

ETHICS IN PRACTICE 6-1

Medical Assistance in Dying: Challenges to Moral Agency

Cindy is a nurse working on a community mental health team in an urban centre. Part of Cindy's job is to provide care for patients who have a chronic mental health condition and need monthly follow-up. Cindy went to visit Esther, a patient with a long history of psychosis and paranoia, who had missed her monthly appointment. Esther’s mental illness had a severe impact on her relationships; she had no friends and had cut off contact with her family about 20 years before. Consequently, Esther was difficult to engage in treatment, and her only support people now were members of the community mental health team. When Cindy saw Esther, she was shocked to see how much weight Esther had lost since their last meeting a month before. Esther, unsteady on her feet, explained that she had food poisoning and had been unable to eat. She did not want to go to the local hospital to be checked out, but the two of them arranged for Cindy to bring some groceries and to check in the following week. At the subsequent visit Esther agreed to go to the local emergency department (ED), as she was very weak, having only been able to drink water. The ED physician discovered that Esther had cancer and that it had spread throughout her whole body. Esther was admitted to a medical unit to manage her symptoms and begin cancer treatment.

Esther stayed in the hospital, and Cindy made arrangements with the cancer agency for treatment. During her visits over a period of three weeks, Cindy noticed that the nurses avoided Esther, mostly leaving her to care for herself. Cindy recognized that the nurses didn't know how to engage Esther, and she was uncomfortable with the lack of care Esther received. One day Cindy called the unit to give details of an upcoming meeting with the cancer agency. During the call, Cindy was informed that the hospitalist had spoken to Esther, who had just agreed to MAID, which would take place within the hour. Cindy rushed to the hospital and found that preparations were in process for MAID. When Cindy asked Esther directly if she understood what was happening, Esther replied, “I don't want to die, I want to go to a boarding home.” Cindy called her manager and together they halted the process. Esther died from her cancer a few days later.

As a result of her experiences trying to support Esther during her hospital care, Cindy described feeling morally distressed for several reasons. She felt angry when she would arrive on the unit and find that Esther had not received even basic care. On the day that MAID was to occur, Esther was filthy. She hadn't been bathed or given clean pajamas, had not had oral care, and had feces on her sheets. Cindy understood that Esther could be difficult to work with, but she couldn't understand why the staff on the unit failed to meet the bare minimum of care for her. Cindy was shocked that the hospitalist had arranged for MAID to happen without speaking to anyone on the community mental health team, the members of whom had been Esther’s only
Location of Moral Distress and Constraints

Early researchers on moral distress highlighted the problems and consequences of locating the experience solely within the individual HCP (the agent), or within health care organizations (structures). If moral distress is considered as an individual experience, then moral distress can be viewed as a flaw within the person (Varcoe et al., 2012), leaving the individual HCP to develop better coping strategies and become more resilient. Alternatively, if moral distress is seen as a result of institutional decisions and processes—for example, economically driven decision making—then the
organization becomes responsible for addressing the issues (Varcoe et al.). Both views reflect opposite ends of a spectrum of moral agency and are problematic because they overlook the shared responsibility of addressing the situations and contexts that create moral distress (Musto et al., 2015).

The nature of constraints on moral agency has also been debated. Initially, constraints on moral agency were identified as located solely within the organization; for example, hierarchical decision making, [limited] autonomy in practice, and constrained resources (Jameton, 1984). However, subsequent researchers identified that constraints on moral agency might also be “perceived” (Wilkinson, 1987), or arise from within an individual’s fear or moral failure (Austin et al., 2003; McCarthy & Gastmans, 2015). Identifying constraints on action (either internal or external to the individual) as the root cause of moral distress is the source of much debate with the definition, which we discuss below. This identification also infers that moral distress is a linear process; either an HCP makes a moral judgment and acts on it and does not experience moral distress, or constraints inhibit the HCP from taking action and they experience moral distress.

From the first research initiatives on moral distress, the perspective of linear causality has been refuted, as Jameton (1993) noted when revising the definition to include “initial” and “reactive” distress (p. 544). In our view, constraints on action and moral agency are necessarily linked but not linear, because HCPs are situated within teams and organizations; as such, constraints on action, and taking action, occur in a relational context (Varcoe et al., 2012). Indeed, Varcoe et al. define moral distress as “a relational experience shaped by multiple contexts, including the socio-political and cultural context of the workplace environment” (p. 59). Currently, scholars and researchers express a nuanced perspective acknowledging the reciprocity between the organizational context and individual HCPs in the experience of moral distress, viewing it as an organizational issue that is reflected in individual HCPs (Epstein et al., 2020).

In Ethics in Practice 6-2, we describe a scenario where a nurse practitioner (NP) is working in an environment where the socio-
political and cultural context plays a significant role in leading to the NP’s moral distress.

ETHICS IN PRACTICE 6-2

Outpost Nursing Practice and Regional Hospital Challenges

Rebecca Saunders is a registered nurse who has practiced in both hospital and community contexts in Ontario for eight years. She has just completed a two-year Masters in Nursing degree to become a nurse practitioner (NP). Rebecca studied relational practice in her NP program, and she has recently been recruited as an NP in a rural nursing station in northern Ontario. She is thrilled to have the opportunity to get to know the diverse community where the nursing station is located, and to learn from her colleagues there. However, she is also aware that she has a great deal to learn about primary care in an outpost context. Further, she knows that she must be cognizant of the unique cultural contexts of the diverse Indigenous and non-Indigenous people living in the community and the surrounding region.

After working for five months at the nursing station, Rebecca has come to appreciate the relational connections that she is making with diverse community members. She is able to practice to her full scope as an NP with mentorship from another NP and a physician who regularly visits the nursing station. However, she is concerned about what many of her patients relay to her regarding their experiences when they are sent for specialized treatment at city hospitals in Ontario or other provinces. Her patients speak of feeling “like a fish out of water” in these busy urban environments. Their appointments are often rushed, and they miss their usual family and community supports. Rebecca worries that these patients are not getting the quality of care that they need and deserve, and she feels helpless to initiate the intra-and inter-provincial system-level changes that she believes are required to make a difference.

REFLECTIVE QUESTIONS

1. What socio-political inequities may be affecting Rebecca’s patients when they are sent away from their home community for specialized treatment in city hospitals?

2. Rebecca studied relational practice and moral distress in her NP program. She is aware that her concerns about her patients’ experiences may be creating moral distress for her and possibly for her colleagues in the nursing station. What are the possible implications for Rebecca and her colleagues in terms of ongoing moral distress?

3. How might the principles of relational practice guide Rebecca’s leadership as a moral agent with her nursing colleagues and the population she is serving?
A Shared Responsibility for Addressing the Moral Context of Practice

What we have described are everyday examples of the moral challenges nurses confront in practice. We have used these examples to expose how socio-political and economic discourses create systemic vulnerabilities at the micro, meso, and macro levels of health care. Failure to connect limited resources, and regulatory bodies, to political and economic decision making gives the appearance that the moral context of health care practice is the sole responsibility of health care organizations. This neglects the reality that funding for health care organizations and regulatory bodies is determined at the macro level of the provincial and federal governments. We need to acknowledge that decisions at the macro level are made primarily by individual organizational leaders, which is also true of decisions made at the micro and meso levels of the health care system.

The responsibility to navigate ethical challenges, repair moral wrongdoing, and promote ethical practice is a shared responsibility. The moral context in which nurses practice shapes their ability to enact their moral obligations to patients. In turn, nurses’ actions influence the context in which they work. Individuals at all levels of the health care system (micro, meso, and macro) have the capacity to enact their moral agency to varying degrees when they encounter ethical challenges in practice. Those in positions of leadership bear the preponderance of responsibility to foster a positive moral context of practice, because they hold the macro level authority for financial resources, decision making, and shaping organizational cultures. In Figure 6-1, we represent these relationships in terms of reciprocity between structures (health care environments) and agents (nurses and other HCPs).

4. How might Rebecca find ways to engage with nursing and medical leaders in her community and at the city hospitals regarding the relational needs of the patients in her community? How might she involve colleagues, patients, and other community members in these activities?
Research: The Influence of Context on Moral Agency

Drawing on the work of Milliken (2018) and others, we view moral agency as a dynamic and relational process that is influenced by the context(s) in which an individual works. The enactment of moral agency was the focus of research conducted by two authors of this chapter, Musto and Rodney, as well as their colleagues (Musto et al., 2021). As part of her dissertation work, Musto (2018) examined how HCPs working in mental health enacted moral agency in ethically challenging situations. The participants revealed that being a moral agent required balancing their own professional identity with the risk of having their professional reputation, their job, or their status on the health care team called into question. It is important to note that although all participants were able to describe how they enacted their moral agency, the contexts of participants’ practice...
environments at micro, meso, and macro levels played a significant role by either supporting or constraining their actions.

Musto (2018) found that the willingness of participants to take professional risks depended on the participant’s context. The theoretical themes that Musto developed in her research appear in italics in the text that follows. In Figure 6-2 (from Musto, 2018), the outer portion of the diagram represents the socio-political context of HCPs’ practice, and the inner segments represent key findings and related theorizing. As shown on the left side of Figure 6-2, offloading responsibility for care is part of the background context of this study and occurred between disciplines, hospital departments, and units, as well as between hierarchical levels of the health care organization. One of the consequences of government agencies offloading responsibility of care was that the acute care mental health programs took up responsibility for these complex patients. The result was that participants in the study noted a rise in the admission of two specific population groups into acute care psychiatric units: patients with a dual diagnosis and patients with a forensic history. As shown on the right side of Figure 6-2, safety and high-stakes situations permeated the background context of this study and refers to the increased levels of risk for significant harm, or aggression, including death.

Participants who described working with supportive colleagues and managers (Working Through Team Relationships) were encouraged by colleagues and their direct supervisors to raise and work through ethical issues. Team members supported participants by suggesting strategies or avenues for advocacy, and helping each participant to recognize the boundary of their responsibility. Participants who were supported described their growth as moral agents. For example, they developed strategies for advocacy and had increasing confidence in their ability to advocate; they carried forward these changes as they navigated subsequent ethical challenges; and they also discussed tipping in and out of moral distress, but not feeling “stuck” in the experience.

Musto also indicated that participants who described working in an unsupportive or toxic environment experienced a high degree of risk to their professional reputation—and their job, in some situations—if they attempted to address ethical challenges
directly, which she identified as *Struggling With Inhumanity* (Musto et al., 2021).

Participants often related situations of poor practice or bullying, but indicated that to speak up meant that a participant opened themselves up to retaliation. In some cases, the perpetrator of bullying was their direct supervisor or manager. Participants in these work environments perceived their direct supervisor or manager as providing ineffective leadership because leaders failed to intervene by holding practitioners accountable to their standards of practice or code of ethics. In these instances, to protect
themselves while also taking action, participants directed their moral agency towards the person in front of them—their patient or co-workers—in an attempt to mitigate [the experience of] ethical wrongdoing and the experience of moral distress.

A few participants in Musto’s (2018) research described situations where they chose to be moral agents regardless of the consequences, because by not acting they were risking their own sense of integrity and perception of their professional identity—as described in Musto’s framework, they were Pushing Back. Participants in this category discussed having developed personal strategies over time, such as spiritual practices, or developing a network of colleagues to go to for advice, that helped them to recognize when it was necessary to take what they described as “big actions” (Musto, 2018, p. 224) and advocate for system change. Some participants who took big actions either lost their jobs or moved on when no change was possible, but they acted in alignment with their professional identity, so their integrity remained intact. Other participants took big actions and were successful in creating the changes they sought. All participants who pushed back described that the strategies they had learned over time made it possible for them to live with the experience of moral distress that resulted from working in health care.

All participants enacted moral agency to different degrees depending on their context. They also described a range of individual and organizational strategies necessary to fully exercise their moral agency and live up to their professional and ethical obligations of practice, which highlights the dynamic nature of being a moral agent as described by Milliken (2018). Musto (2018) emphasized how the responsibility for ethical practice was shared, perhaps even entangled, between HCPs and health care organizations. This is depicted in Figure 6-2, with a particular emphasis on the need for leaders who support the enactment of moral agency.

In Musto’s (2018) research on moral agency, participants explicitly linked moral agency to the experience of moral distress. As our understanding of moral distress evolves through the work of Musto and other scholars, there is growing consensus that a central source of moral distress is compromised professional identity (Epstein et al., 2019; Guzys, 2021).
Evolving Definitions of Moral Distress

Musto (2018), in her research, illustrated the significance and impact of moral distress on HCPs. In what follows, we review some of the scholarly debates that continue to evolve regarding the nature of and impacts generated by moral distress. While the experience Jameton (1984) described resonated with nurses, the actual definition he ascribed to the experience has been critiqued and debated over the past two decades, and these debates continue. In the initial description of moral distress, Jameton stated that “[m]oral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (p. 6). Several scholars have written thoughtful critiques of moral distress (see for example, Fourie, 2015; Hanna, 2004; Johnstone & Hutchinson, 2015; McCarthy & Deady, 2008). Our focus in this section is to provide an overview of the evolution of the concept as a response to critiques of the definition (see Table 6-2). This table is not intended to be an exhaustive list of definitions of moral distress; rather, we present a sampling of definitions that represent the debates surrounding moral distress over time. Earlier in this chapter, we identified some of the assumptions underpinning the original articulation by Jameton (refer to the section titled “Basic Assumptions Underpinning the Definition”). We continue here with a discussion of critiques and subsequent adjustments in our understanding of the concept of moral distress in response to these critiques. We end this section by pointing to how the definition of moral distress can be used in diverse areas of research and practice.
### Selected Definitions of Moral Distress

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<th>Authors</th>
<th>Definition</th>
<th>Critiques, Assumptions, and Subsequent Evolution</th>
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<tr>
<td>Jameton (1984)</td>
<td>Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action (p. 6).</td>
<td>Introduction of moral distress into the nursing lexicon. Captures the ideas of making a moral judgment, being unable to act on that judgment, and organizational constraints.</td>
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<td>Jameton (1993)</td>
<td>Initial moral distress involves the feelings of frustration, anger, and anxiety people experience when faced with institutional obstacles and conflict with others about values. Reactive moral distress is the distress people feel when they do not act upon their initial distress (p. 544).</td>
<td>Amended the definition following Wilkinson's (1987) work to capture one of the assumptions, that moral distress has a linear trajectory, e.g. if a nurse took action in the face of moral challenge, they would not experience moral distress.</td>
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<td>Wilkinson (1987)</td>
<td>Moral distress is the psychological disequilibrium and negative feeling state experienced when a person makes a moral decision but does not follow through by performing the moral behaviour indicated by that decision (p. 16).</td>
<td>Illuminates some of the gaps/assumptions in the definition.</td>
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<td>• Moral distress is a linear and binary experience hinged on action or non-action.</td>
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<td>• Moral situations can take other paths, e.g. moral outrage.</td>
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<td></td>
<td>• Identifies constraints as being real (institutional/external), or perceived (internal) by the nurse.</td>
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<td></td>
<td>• Speculates on the influence of moral distress on quality of patient care.</td>
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<tr>
<td></td>
<td>• Attributes “distress” as psychological.</td>
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<td>Austin et al.</td>
<td>Moral distress is the state experienced when moral choices and actions are thwarted by constraints. Responses to such constraints include frustration, anger, helplessness, despair, and/or betrayal (pp. 177–178).</td>
<td>Extended research to include other disciplines, and in the area of psychiatry. The word “betrayal” exposes the assumption of shared responsibility of ethical practice. The expectation that the HCP will practice according to their code of ethics, and that health care organizations will provide the resources for ethical practice.</td>
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<td>(2003)</td>
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<td>Kålvemark et al.</td>
<td>Traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the HCP feels she/he is not able to preserve all interests and values at stake (pp. 1082–1083).</td>
<td>Broadened research to include both HCPs in direct care and HCPs in non-direct care (pharmacists and pharmacy technicians, medical secretaries). Findings challenged original definition, i.e., moral distress could arise in situations of moral dilemmas.</td>
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<td>(2004)</td>
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<td>Nathaniel</td>
<td>Moral distress is pain affecting the mind, the body, or relationships that results from a patient care situation in which the nurse is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action; yet, as a result of real or perceived constraints, participates, either by act or omission, in a manner he or she perceives to be morally wrong (p. 421).</td>
<td>Critiques the definition of moral distress as being narrow, and failing to explain the long-term processes that nurses experience; assumption that the nurse participates in the wrongdoing and is confined to the psychological implications setting up an “us-against-them” mentality. This critique is picked up by others as potentially perpetuating a victim narrative in nursing.</td>
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<td>(2006)</td>
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<td>Mitton et al.</td>
<td>Moral distress is the suffering experienced as a result of situations in which individuals feel morally responsible and have determined the ethically right action to take, yet due to constraints (real or perceived), cannot carry out this action, thus believing that they are committing a moral offence (p. 108).</td>
<td>This was one of the first studies to examine moral distress in middle managers of health care organizations. Explicitly shifts research to meso level of health care organization by clearly identifying situations in which managers felt they were forced to violate strongly held moral/ethical principles.</td>
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<td>(2011)</td>
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<td><strong>Varcoe et al.</strong> (2012)</td>
<td>Moral distress is the experience of being seriously compromised as a moral agent in practicing in accordance with accepted professional values and standards. It is a relational experience shaped by multiple contexts, including the socio-political and cultural context of the workplace environment (p. 59).</td>
<td>Explicit connection of moral distress to moral agency and violation of professional (not personal) values and standards. Introduces the idea of moral distress as a relational experience.</td>
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<td><strong>Crane et al.</strong> (2013)</td>
<td>The experience of psychological distress that results from engaging in, or failing to prevent, decisions or behaviours that transgress, or come to transgress, personally held moral or ethical beliefs (p. 6, emphasis in original).</td>
<td>Author critiques assumption of non-autonomous decision making causing moral distress, which may not be the case; and that for moral distress to occur one must knowingly contravene one’s values, which doesn’t allow for moral distress to arise as an unforeseen consequence of one’s decisions. Draws on organizational psychology to explain moral distress.</td>
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<td><strong>Fourie</strong> (2015)</td>
<td>Moral distress should be understood as a specific psychological response to morally challenging situations such as those of moral constraint or moral conflict, or both (p. 92).</td>
<td>Critique that the definition is a “narrow” and compound definition that requires constraints as a causal mechanism. Recommends removing “constraints” as a necessary condition of moral distress and including moral conflict as a potential cause.</td>
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<td><strong>Campbell et al.</strong> (2016)</td>
<td>Moral distress=df one or more negative self-directed emotions or attitudes that arise in response to one’s perceived involvement in a situation that one perceives to be morally undesirable (p. 6, emphasis in original).</td>
<td>Present an argument for broadening the definition of moral distress to include other forms of moral distress not directly related to knowing the right course of action. Campbell et al. argue that moral distress arises when one feels morally compromised in some way.</td>
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Broadening the Definition of Moral Distress

As research on and critiques of moral distress have opened up challenges with the original definition, some scholars have proposed new definitions or suggestions for responding to the critiques. We provide a brief summary of this debate here, and encourage readers to review the arguments from primary sources (see for example, Fourie, 2015; Hanna, 2009; Johnstone & Hutchinson, 2015; Morley et al., 2019). In our summary, we focus on two connected but separate aspects of the debates: broadening the definition beyond moral certainty (knowing the right course of action) to include a range of moral situations such as moral uncertainty and moral conflict (Campbell et al., 2016; Crane et al., 2013; Fourie), and removing “constraints” as a cause of moral distress from the definition (Fourie; Morley et al., 2019, 2021).

In 2016, the American Journal of Bioethics published an edition that included a debate on the pros and cons of expanding the definition of moral distress. Leading the edition, Campbell et al. (2016) argued for a definition of moral distress that could accommodate a range of situations that “can be sensibly framed as moral distress” (p. 2). The authors presented six ethical cases that potentially embodied the experience of moral distress and contributed to

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<td>Morley et al.</td>
<td>To be properly labelled moral distress it seems necessary that the distress is directly causally related to a “moral event.” This would be a combination of (1) the experience of a moral event; (2) the experience of “psychological distress”; and (3) a direct causal relation between (1) and (2) are necessary and sufficient conditions for moral distress (p. 660).</td>
<td>Conducted a narrative synthesis of the literature reviewing 20 definitions of moral distress to determine the “necessary and sufficient conditions” of moral distress. Explicitly linking psychological distress to a moral event as a requirement of experiencing moral distress.</td>
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*Note: All the definitions given in Table 6-2 are direct quotes from the references listed.*
a loss of provider well-being. The cases included situations of moral uncertainty, mild distress, delayed distress, moral dilemma, bad moral luck, and distress by association (pp. 4–6). Campbell et al. offered a new definition of moral distress as being “[o]ne or more negative self-directed emotions or attitudes that arise in response to one’s perceived involvement in a situation that one perceives to be morally undesirable” (p. 6). This definition is broad enough to accommodate the range of situations that these researchers presented in their article.

Nonetheless, researchers on moral distress have pushed back on suggestions to broaden the definition, such as the one offered by Campbell et al. (2016), because the proposed definitions are so broad as to be “diagnostically and analytically meaningless” (Wocial, 2016, p. 21). As well, Hamric (2012) highlighted that the “problem of different definitions compounds the difficulty of developing adequate measures, since how a concept is defined matters greatly in measurement. Valid measures require a tight linkage between the concept and the items developed for the measure” (p. 44). Thus, developing a measurement tool for moral distress using a broad definition with ambiguous concepts would likely be impossible.

A second theme in the debate about broadening the definition of moral distress rests on removing the requirement of “constraints” on moral action. Fourie (2015) advocated for the removal of moral constraints from the definition as a necessary condition of the experience of moral distress. Fourie also identified Jameton’s definition of moral distress as “narrow” because it “stipulates a particular cause, i.e., moral constraint” (p. 92), excluding other possible causes, such as moral uncertainty or moral conflict. Fourie offered a revised definition, stating that “[m]oral distress is a psychological response to morally challenging situations such as those of moral constraint or moral conflict, or both” (p. 97).

While Fourie’s argument for excluding constraints from the definition of moral distress has support (Morley et al., 2019), McCarthy and Monteverde (2018) provided a particularly convincing argument of the consequences of broadening the definition by removing constraints. These authors pointed out that “[f]or Jameton, situations involving moral constraint and moral distress prompt questions about moral responsibility and agency that
moral agents *cannot evade*” (McCarthy & Monteverde, p. 324, emphasis in original). Perhaps most important from our perspective is that McCarthy and Monteverde highlighted that broadening the definition of moral distress diverts attention away from “the way in which institutional and/or socio-political structures undermine [health care professionals’] moral agency. There is a danger then, that unless empirical research pays explicit attention to the role of these external constraints, they will be rendered invisible” (p. 325). Keeping constraints as a condition of moral distress invites both empirical research and critique of the socio-political and economic contexts that shape health care delivery. This kind of critique goes beyond examining constraints on moral agency to an exploration of contradictions between explicit societal values about equitable access to health care and political decisions related to resource allocation or funding models.

Broadening the definition of moral distress carries risks. The first risk is that the definition becomes so broad as to become meaningless. The second, related, risk is that it becomes difficult, if not impossible, to conduct research on such a broad topic. To overcome these risks, Campbell et al. (2016) suggested the development of a taxonomy of moral distress that could both identify specific forms of moral distress and accommodate research. Drawing on the extant literature, the authors suggested a taxonomy of moral distress that could be organized around “three components of moral distress: the negative attitudes that one experiences, one's perceived involvement in the situation, and the perceived moral undesirability of the situation” (p. 8). Other alternatives, such as developing a taxonomy for moral distress rooted in professional moral integrity (Thomas & Bruce, 2016), or in the specific causes of moral distress (Fourie, 2015), have been suggested as means of addressing the lack of conceptual clarity with the concept. The last risk of broadening the definition we highlight relates to Jameton's attempt to capture the embodied experiences nurses described when they were unable to live up to their moral obligations to their patients. McCarthy and Monteverde (2018) referred to this as “the lived experience of HCPs” (p. 325), and described it as a strength of Jameton's definition, reminding us that broadening the definition risks obfuscating the felt experience of moral violations.
Keeping a Narrow Definition of Moral Distress

Debates on the definition have moved scholars and researchers towards a greater understanding of moral distress, bringing the complexity of moral decision making and moral agency to the fore. Having said this, we land on the side of maintaining Jameton’s “narrow” definition of moral distress. As noted above, maintaining constraints as part of the definition makes explicit that moral distress occurs at the intersection between the health care environment and moral agency. As such, we believe that addressing moral distress remains a shared responsibility among HCPs and health care organizations.

Guzys (2021) offered an example of understanding and addressing moral distress as a shared responsibility by describing a relational perspective of the experience. Guzys identified the fundamental cause of moral distress as being a “disorientation of professional identity resulting from conflict between a nurse’s professional values and constraints imposed on professional practice” (p. 659). Recognizing the interplay between the individual’s (agent’s) professional values and organizational (structural) constraints, Guzys drew on theoretical work that acknowledges the reciprocity between top-down and bottom-up influences at the micro, meso, and macro levels. Thus, Guzys explicitly located moral distress at the intersection of structure and agency, so that addressing moral distress becomes a shared responsibility between HCPs and health care organizations.

In order to develop meaningful interventions for HCPs, researchers must be able to measure the phenomenon and the effectiveness of interventions. The shared responsibility for addressing moral distress requires that interventions be multifaceted and directed at the micro, meso, and macro levels of the health care system. As a concept, moral distress has received considerable attention, theoretically and empirically, both qualitatively and quantitatively. Nonetheless, there remains a need for ongoing and rigorous theoretical and empirical work. Over the past two decades, progress has been made regarding the measurement of moral distress, with a goal of informing action to prevent and ameliorate the experience. Hamric and colleagues (2012) revised Corley et al.’s
(2001) original moral distress scale by developing the Moral Distress Scale—Revised, and subsequently, (Epstein et al., 2019) developed the Measure of Moral Distress for Healthcare Professionals (MMD-HP). These are instruments in which respondents assess the frequency and level of distress that is associated with specific situations. The most recent measurement tool, the MMD-HP, is usable across HCPs and health care settings (Epstein et al.). Next, we describe a program of research on moral distress in critical care conducted by Dodek and his colleagues. The research conducted by Dodek’s team, and their subsequent findings, are an example of the importance of empirical approaches to understanding moral distress and developing interventions that support the moral agency of HCPs at all levels of the health care system.

**Moral Distress—Measurement to Action**

The critical care setting is an appropriate place to explore moral distress because this is where many ethical issues arise. Considering the high stakes of critical illness and its treatments (such as mechanical ventilation, dialysis, vasoactive drugs, and extra-corporeal life support), there are many situations in which there is disagreement between what a critical care professional believes is “right” for the patient, and decisions that are made by others in the care team, including the patient’s family. These disagreements may pertain to individual treatments or to the overall direction of care (for example, attempts to cure versus provision of comfort with an expectation of death). Furthermore, there may be differences between front-line critical care professionals and their supervisors about what is considered safe care, or adequate resources to deliver care. Such conflicts in values can cause moral distress.

In Ethics in Practice 6-3, we analyze the moral distress experienced by a nurse working in an intensive care unit (ICU), and consider the implications for their current and future practice, as well as the practice of other nurses.
ETHICS IN PRACTICE 6-3

Moral Distress Experienced by a Novice ICU Nurse

Jordan Singh is a 28-year-old registered nurse who works in an intensive care unit (ICU) in a large urban hospital. Jordan commenced ICU practice after completing his nursing education at a community college in Saskatchewan. He worked on an acute medical unit in Toronto for eight months, and then, most recently, completed a six-month-long ICU course.

Jordan greatly appreciates the learning he is acquiring as a new practitioner in the ICU, and finds the mentorship provided by the expert nursing and medical staff he works with to be helpful and inspiring. However, he also finds that he goes home after almost every shift feeling physically exhausted, and emotionally troubled by the serious and uncertain prognoses his patients and their families are often facing. He finds himself with less energy to engage with his family and friends or enjoy his favourite activity, horseback riding. He wonders if his feelings are normal, or if he might be “too sensitive” for the rigours of ICU practice. Jordan has heard some of his colleagues talking about moral distress, and he wonders if that is what he is experiencing. Yet, when he approaches the nurse educator to talk about moral distress, she tells him, “Hey, you'll get used to it.”

REFLECTIVE QUESTIONS

1. Do you think Jordan is experiencing moral distress? In what way(s) does Jordan’s story reflect Jameton’s definition of moral distress?

2. What do you think about the nurse educator’s response to Jordan’s concerns?

3. What preventative and supportive measures do you think could help Jordan now and as his career progresses?

4. What responsibilities do leaders in the ICU have to help Jordan and other HCPs to prevent them from experiencing moral distress?

5. How might advanced practice nurses, such as nurse educators and other nurse leaders, better prepare nurses at any stage in their careers to prevent, manage, and recover from moral distress?
Impact of Moral Distress on Health Care Professionals and Patient Care

Dodek et al. (2016) explored the magnitude of moral distress in critical care professionals, by surveying all professional staff in 13 Canadian ICUs using the Moral Distress Scale—Revised. The researchers found that the moral distress score was higher in ICU nurses and other non-physician professionals than in physicians; was higher in nurses with more years of experience but was lower with older age for other non-physician professionals; and was associated with a tendency to leave the job. The highest-ranked items associated with moral distress were related to end-of-life controversies and resource constraints. To examine concomitant issues and consequences of moral distress, they also surveyed the same professionals regarding general workplace distress (Dodek et al., 2018), and measured safety outcomes in the participating ICUs (Dodek et al., 2019c). After adjustment for demographic characteristics, higher moral distress in nurses was associated with lower decision latitude and social support, and with higher psychological stressors and psychological strain (Dodek et al., 2018). These relationships were similar for physicians and other professionals. Although moral distress in ICU personnel was generally not associated with errors or adverse events related to medications, or other adverse events, it might be associated with both hyper-vigilance in nurses and distraction in physicians (Dodek et al., 2019c).

To further explore these findings, Henrich (2016, 2017) conducted focus groups in three ICUs. The most commonly reported causes of moral distress were concerns about the care provided by other health care workers, the amount of care provided (especially too much treatment at end of life), poor communication, inconsistent care plans, and issues around end-of-life decision making (2016). All of these causes are amenable to improvement. Reported consequences of moral distress included frustration, perception of a negative impact on patient care, and thoughts about quitting work in the ICU (Henrich, 2017). These consequences indicate that moral distress is not just a psychological phenomenon—rather, it has grave potential consequences for both health care professionals and their patients.
Assessing Generalizability of Findings

To explore the generalizability of these findings, Dodek et al. (2021) surveyed all critical care physicians in Canada using the MMD-HP. Overall, they found a moderate level of moral distress, and levels of moral distress were lower in those who had partners compared to those who did not have a partner. The highest-ranked item scores on the moral distress instrument were those related to overly aggressive and potentially non-beneficial treatment, lack of resources, and lack of administrative action and support. In addition, there were significant associations between moral distress and burnout and moral distress and compassion fatigue, but notably, there was no association between moral distress and a validated measure of personal resilience. Qualitative analysis of free-text comments on the surveys revealed that a combination of contextual and relational factors led to moral distress and other kinds of workplace distress, which in turn led to individual and collective negative consequences such as burnout and attrition (Piquette, 2019). These consequences were mitigated in part by individual coping strategies and the rewards of providing critical care. Interviews of some of the survey respondents revealed various approaches to moral conflicts, including self-preservation strategies, patient-oriented strategies, and relationship-oriented strategies (Piquette, 2019). In addition, modulators of moral distress included clinical circumstances, team interactions, legal context, and societal expectations. These modulators are amenable to educational and/or organizational intervention.

Considering these observations in practicing critical care professionals, Sajjadi et al. (2017) decided to look “upstream” by surveying post-graduate physicians and medical students. In a cross-sectional survey of internal medicine residents, Sajjadi and colleagues found a relatively low level of moral distress, but more than a quarter of respondents had considered quitting their residency due to moral distress, and moral distress was associated with burnout. Furthermore, the rotations associated with the highest levels of moral distress were in intensive care units and clinical teaching units (in-patient medicine). These observations informed next steps regarding investigating causes of moral distress.
in these residents. In a cross-sectional survey of medical students, researchers also found a “mild” level of moral distress (Dodek et al., 2019a), and no relationship between coping strategies and moral distress (Dodek et al., 2019b).

**Moving to Informed Action**

Although further work is necessary to explore modifiable determinants of moral distress, its consequences (including attrition) require interventions. Given the individual nature of moral distress, one place to start is to help individuals characterize and work through their moral conflicts using a participatory approach. Chevalier, Dodek, and colleagues developed an explicit moral conflict assessment model (2022) that tested this approach in both individual and group sessions with 23 participants from three ICUs. This approach was feasible and well-received by the participants, but further experience and evaluation is needed. In the meantime, HCPs and their leaders can begin to ameliorate moral distress, first by recognizing it as a psychological phenomenon that is distinct from other causes of workplace distress, and then addressing the components of the moral conflict that usually underpin this distress. For example, conflicts related to end-of-life care can be addressed by promoting advance care planning, and by routinely considering a palliative approach for eligible patients (Venis & Dodek, 2020). Conflicts related to communication and consistency of care can be addressed by teamwork training (Clancy & Tornberg, 2019). Conflicts related to resource allocation can be addressed by involving front-line professionals in these decisions. Each of these examples requires leaders who are actively engaged with their personnel, and allot time for front-line professionals to participate in improvement work. Quantitative and qualitative inquiry would be helpful to measure the impact of these interventions, attitudes, and skills.

**Future Avenues of Inquiry**

Dodek and his colleagues have presented an example of a program of research on moral distress by a Canadian team of health care researchers using a combination of quantitative and qualitative
methods. The researchers have identified several modifiable causes of moral distress that are amenable to improvement (Henrich et al., 2016). Yet, many questions remain unanswered: Who gets moral distress? Are there modifiable characteristics that predict this phenomenon in health care professionals? What are the causes and consequences of moral distress in health care leaders and decision makers? Where does moral distress occur—is there a relationship to organizational culture? And if so, what are the modifiable characteristics of the workplace that can ameliorate moral distress? Do patients and their family members get moral distress? If so, what are the modifiable determinants of their distress, and is there a relationship between their distress and moral distress in their HCPs? Can teams benefit by forming communities of practice related to preventing and ameliorating moral distress, or by studying success factors in sites that have less moral distress? Further theoretical and empirical work is needed in order to answer these questions. However, theoretical and empirical work alone is insufficient to effect change in health care environments. Moral leadership within health care organizations is also necessary to support interventions that address and ameliorate moral distress.

**Recommendations to Influence Change Through Moral Leadership**

In this chapter, we have endeavored to track the evolution of the concept of moral distress, which nurses and other HCPs may experience as a result of the ethically complex situations they encounter in practice. We began by defining moral distress and differentiating it from other, overlapping concepts. Then we delineated the reciprocity between the moral context of nursing practice and moral agency. Next, we shifted our focus to some of the key debates surrounding moral distress, which allowed us to highlight gaps in our current knowledge base. At the same time, these gaps serve as signposts to guide further research and the development of interventions that support the moral agency of nurses and other HCPs in addressing moral distress. Below, we provide recommendations for addressing moral distress. We recognize that addressing moral dis-
tress requires simultaneous, multi-pronged approaches at micro, meso, and macro levels of the health care system.

To begin, further theoretical and empirical work is necessary to answer questions that remain unsettled in the definitional debates around moral distress, including how to move toward strategic action. Fourie’s (2015) interrogation of the compound nature of Jameton’s 1984 definition of moral distress is one example of theoretical work supporting a more robust understanding of moral distress. Furthermore, McCarthy and Monteverde (2018) have pointed to the need for investigations of the link between moral emotions, moral judgment, and moral action in the experience of moral distress. Understanding the role of moral emotions may explain why some HCPs who experience moral distress become more attentive to their individual patients (micro level response) (Musto et al., 2021; Wilkinson, 1987), while others direct their actions towards instigating systemic (meso or macro level) change (Musto et al., 2021).

Theorizing about moral emotions will also assist in distinguishing moral distress from other closely related concepts such as burnout, compassion fatigue, and vicarious trauma—while at the same time potentially clarifying the distinction, or transition, between moral distress and moral injury in health care. Theorizing about how to address power dynamics between health care disciplines and hierarchical positions within health care organizations is a particularly worthwhile area for exploration and speculation about interventions to prevent and/or ameliorate moral distress.

Qualitative and quantitative empirical research on moral distress, (for example, Dodek et al.’s program of research presented earlier in the chapter), is ongoing across disciplines, settings, and specialty populations. One of the particular strengths of empirical research is the opportunity for researchers to assess the effectiveness of specific interventions. Researchers using quantitative measures can identify potential decreases in moral distress experienced by nurses and other HCPs following interventions, whereas researchers using qualitative methods may be able to identify why the interventions were effective. This can allow researchers and HCPs the opportunity to explore—and ultimately address—the complexity of the lived experiences of HCPs within complex health
care contexts. Such contextually based inquiry makes it possible for researchers, advanced practice nurses, and other health care leaders to work with HCPs to develop effective interventions at micro, meso, and macro levels of health care delivery. In what follows, we outline interventions that we believe have promise at all levels of health care delivery. These interventions have been informed by related scholarship and research, and would also benefit from ongoing qualitative and quantitative evaluative research.

At the micro level, nurses can use strategies to improve moral resiliency to decrease moral distress (Rushton, 2016). Individualized self-care strategies, including spiritual, emotional, physiological (diet and exercise of some form), and psychological practices that support the wholeness of HCPs can be useful. In addition, strategies for developing critical reflection on practice, with supportive mentoring from colleagues and supervisors, can be significant in helping to ameliorate moral distress. These self-care strategies need to be meaningful to the individual, not simply prescribed by health care organizations or regulatory bodies.

Addressing the concept of critical resilience can be beneficial in promoting and supporting strategies at all levels. In a book addressing “survival” and “change” for nurses in the United Kingdom, Traynor (2017) emphasized that “[t]he combination of becoming informed about the political and policy forces acting on day-to-day working experience and frank, mutually supportive discussion can develop critical resilience” (p. 30). Traynor also stressed that discussion and information must be used in a complementary manner, explaining that neither “on its own is enough” (p. 30). We take Traynor’s recommendations to be foundational to effective interventions at all levels in all practice arenas. Interventions that we believe would benefit from empirical research include

- Implementation of communication tools to support effective team communication;
- Team-based education and strategies for addressing moral conflict; for example, moral conflict assessment (Dodek et al., 2022), and implementation or adaptation of Pediatric Ethics and Communication Excellence (PEACE) rounds (Wocial, 2017);
- Support for the involvement of nurses and other HCPs in multidisciplinary meetings (Morley et al., 2021); and
- Ensuring that the input of front-line nurses and other HCPs is consistently considered and addressed in health care environments.

Challenges during the COVID-19 pandemic have often meant that interventions to address moral distress, or other workplace problems, have been difficult to implement. For example, Havaei et al. (2021), working from the University of British Columbia School of Nursing, examined the impact of COVID-19 workplace conditions on nurses’ mental health outcomes. They found disturbingly high rates for post-traumatic stress disorder (47%); anxiety (38%); depression (41%); and high emotional exhaustion (60%). In addition, these researchers discovered that nurses who reported adverse mental health outcomes also gave negative ratings about workplace relations, organizational support, organizational preparedness, workplace safety, and access to supplies and resources.

Havaei et al. (2021) concluded that because of the negative mental health self-reports by nurses during the COVID-19 pandemic, better workplace policies and practices were urgently needed to prevent and mitigate nurses’ suboptimal work conditions. Havaei et al. emphasized that their findings support two decades of research showing that the ability of nurses to give their patients effective care is influenced by the workplace conditions of nurses. These research findings have significant implications for promoting the psychological and moral well-being of nurses, and, thus, for improving the overall moral climate for nursing practice and patient care.

Developing interventions for strengthening supportive leadership can be effective in reducing moral distress at the meso and macro levels, and includes strategies such as (a) ethics education; (b) teaching leaders how to apply ethical frameworks; and (c) supporting nurse leaders to be effective mentors (Musto et al., 2021). As mentioned above in work by Dodek et al. (2016), researchers in moral distress have noted the impact on practitioners across disciplines and have indicated that nurses experience higher levels of moral distress than HCPs in other disciplines (Dodek et al., 2016;
Epstein et al., 2019). However, across disciplines the experience of moral distress has been linked to compassion fatigue and burnout, and a willingness to leave the profession (Epstein et al., 2020). Given the impact of moral distress on practitioners, it is imperative to begin preparing nursing and other health care students for the ethical challenges they will inevitably encounter in the work setting.

Guzys’s (2021) model of factors influencing the development of moral distress across the micro, meso, and macro levels of health care is a helpful starting point for developing strategies and interventions to address moral distress. Guzys’s model also reflects the shared responsibility for fostering a resilient health care work force. Professional identity of a practitioner is central to the model, and Guzys presents a curricular guide to mitigating the influences of moral distress. Theorizing about how to address power dynamics between health care disciplines and/or hierarchical positions within health care organizations is a particularly worthwhile area for exploration about interventions to prevent or ameliorate moral distress. For student nurses, it is important to foster self-awareness so they come to understand their own values, knowledge, assumptions, and attitudes. It is essential to introduce students to the concept of critical reflective practice that requires practitioners to “ask critical questions of themselves and their practice through a consideration of the moral, ethical, and sociohistorical contexts of their practice” (Guzys, 2021, p. 662). For example, teaching students effective communication skills for practice, and teaching them how to recognize and communicate respectfully and helpfully in situations that involve values conflicts, will help mitigate moral distress in their future practice. Nurses must have more than a simple awareness of the existence of a professional code of ethics. Teaching nursing ethics and professional ethics is required, so that students are able to deal effectively with moral distress (Guzys, 2021). As part of their professional identity, students need to understand the moral nature of the nurse-patient relationship in a way that provides support for quality care and serves as a foundation for moral courage. Further, assisting students to develop leadership skills, and teaching them about ways to influence change, is essential as they develop their professional identities. Student education
should also include the involvement of relevant provincial, territorial, and national professional associations.

Researchers studying interventions to address moral distress regularly call for the creation of moral communities within organizations to mitigate some of the factors that contribute to moral distress. Epstein et al. (2020) defined moral communities as “groups of people bound together for a common moral purpose that transcends personal interests and promotes the well-being of others” (p. 147). Similarly, the Canadian Nurses Association (CNA, 2017) stated that a moral community is “a workplace where values are made clear and are shared, where these values direct ethical action and where individuals feel safe to be heard (adapted from Rodney et al., 2013a)” (p. 24).

Theorizing about how to address power dynamics among HCPs within health care organizations is a worthwhile area for exploration about interventions to prevent and/or ameliorate moral distress. This requires supporting the involvement of nurses and other HCPs, in unit organization-wide committees, as well as health care agency groups and committees. Advanced practice nurse leaders are key to developing processes to ensure the involvement of nurses and other HCPs in fostering safe moral communities where all their voices are heard.

As described above, research conducted about moral distress has significant implications for leadership action at micro, meso, and macro levels for physicians, nurses, and other HCPs. For example, at the individual level, it is clear that all HCPs ought to have consistent access to expert and supportive mentors with whom they can debrief and seek ethical and emotional support. Such support can help to build resilience of individuals and teams. As mentioned earlier, Traynor (2017) developed a focus on critical resilience for nurses. He explains:

For me the key difference between resilience and “critical resilience” is that critical resilience is about understanding ourselves and our experiences in relation to our society—to take a phrase from feminist consciousness-raising groups (Chicago Women’s Liberation Union, 1970). The combination of becoming informed about the political and
policy forces acting on day-to-day working experience and frank, mutually supportive discussion can develop critical resilience. (pp. 29–30)

Conclusion

Moral distress often results when HCPs believe that they have contributed to wrongful harm, or violated their professional obligations, leading to the suffering of other people. In this chapter, we have argued that addressing moral distress is a responsibility that is shared among health care organizations, those in positions of leadership, and individual practitioners across all health care disciplines. Central to our argument is the recognition that an individual’s enactment of moral agency is dynamic and is shaped by the context in which HCPs work. We provided theoretical perspectives and definitions related to moral distress and moral agency. In addition, we made recommendations for changes that are needed in order for nurses and other HCPs to work in environments where moral distress is no longer a prevalent feature of their practice. We discussed why a multi-pronged approach is required for meaningful interventions at the micro, meso, and macro levels of the health care system to prevent or minimize moral distress. In the absence of such interventions, there is a risk of further erosion of health care delivery due to unacceptable levels of moral distress faced by nurses and other HCPs.

QUESTIONS FOR REFLECTION

1. What are the implications of moral distress for nurses and other HCPs in your area of practice?

2. How ought we to educate nurses and other HCPs about moral distress and its implications?

3. What actions might advanced practice nurse leaders take to ameliorate moral distress in their areas of practice?
4. What research studies could advanced practice nurse leaders design to evaluate the effectiveness of interventions meant to address moral distress?

5. How might advanced practice nurse leaders advocate for interventions to address moral distress at micro, meso, and macro levels across Canada?
Endnotes

1 See, for example, Sherwin (1992), Rodney & Varcoe (2012), and Baylis et al. (2008).

2 For more information about the research conducted by the editors of this book, please see Rodney et al., 2002; Storch et al., 2009; and Varcoe et al., 2003.

3 These are instruments in which respondents assess the frequency and level of distress that is associated with specific situations. Using a semi-quantitative scale for each of these components, the product of the scores for frequency and level is the score for each item, and the sum of these products for all items is the overall score. Advantages of this quantitative approach include understanding the strongest determinants of overall moral distress (ranking of items by score), making comparisons within and among groups of respondents, and analyzing associations between moral distress and other measures such as demographics and other measures of wellness. Limitations of this approach include inability to explore causes of moral distress that are not included in the items in these instruments, inability to explore local nuances of items, and inability to explore consequences of moral distress (other than attrition) and potential solutions. These limitations can be addressed by complementary qualitative assessments and participatory action research. Using both contemporary quantitative and qualitative methods, we have explored moral distress and related measures of wellness in critical care professionals, post-graduate medical trainees, and medical students.

References


Toward a Moral Horizon


AGAINST THE BACKDROP OF dynamic social and organizational transitions of the 21st century, in this chapter we provide an exploration of nurse leaders’ moral commitments across a range of organizational spaces, accountabilities, and tensions. Nurse leaders are poised to make significant contributions to health equity on a global scale, shift health care systems, address racism, and attend to pressing relational and human resource needs. However, within the profession of nursing, critiques and evidence have been mounting.
for decades about the barriers and solutions to enacting ethical leadership in nursing and health systems. Nurses have long been concerned about systemic influences on nursing leadership, in particular on the capacity to fulfill everyday ethical accountabilities (Aroskar, 2006; Austin, 2011; Storch, 1994). Despite growing awareness and dissonance, nursing as a profession has not found a way to navigate and disrupt forces oppositional to ethical leadership.

Our central premise in this chapter is that the most pervasive challenges cannot be met by one nurse leader alone; rather, they require the voice and influence of the nursing profession itself. Given this premise, we discuss ways in which contemporary influences on the nursing profession and its governing organizations may lead to inaction and underperformance in enacting ethical leadership for health equity in the current global context. We present scenarios that expose issues of difference and power relations in individual and collective nursing leadership, and we propose questions to guide inquiry and reflections. We strive for clarity in distinguishing and recognizing those characteristics and qualities of ethical leadership in nursing as enacted within the health care system. We situate the discussion in historic and emerging contexts, and present theories and research that hold particular relevance for understanding ethical leadership in nursing. In so doing, we endeavour to explore and extend the conceptualization of ethical leadership in nursing in light of calls to action in health systems and public policy today.

In this new edition of the Toward a Moral Horizon text, we highlight leadership as central to the discussion of nursing ethics. Our focus in this chapter is related to the interface of the values of the nursing profession with current systems, organizations and governments. We strive to enhance understanding of the nursing profession as a moral community through exploration of the question: How do we envision ethical nursing leadership within the profession, as well as within health care organizations and global communities?

**Ethical Nursing Leadership**

The convergence of unprecedented events, including escalating climate change and the global pandemic, highlight societal health
challenges as current and pressing concerns for the nursing profession to address. Just prior to the emergence of the COVID-19 pandemic, the World Health Organization (WHO) highlighted the urgency for the nursing profession to address the global health issues of our time with the declaration of the year 2020 as the International Year of the Nurse and the Midwife (WHO, 2020a). This declaration was followed by the release of the State of the World’s Nursing Report — 2020 (WHO, 2020b) and the Global Strategic Directions for Nursing and Midwifery (2021–2025) (WHO, 2021a). A compelling rationale for this spotlight on the profession is rooted in the conviction held by international governing bodies that “nurses are critical to deliver on the promise of ‘leaving no one behind’ and the global effort to achieve the Sustainable Development Goals (SDGs)” (WHO, 2020b, p. xii). The call to strengthen nurse leadership is in order “to ensure that nurses have an influential role in health policy formulation and decision-making and contribute to the effectiveness of health and social care systems” (WHO, 2020b, p. vii).

The emergence of the COVID-19 pandemic in early 2020 placed a spotlight on the global nursing profession in ways that had not been conceived of in the declaration. In addition, COVID-19 surfaced profound equity issues, including the value and urgency for sustaining a global nursing workforce, and a call for equity in access to knowledge and technologies required to protect populations. These issues include the development and distribution of vaccines and anti-viral medications. In many ways, the pandemic exemplifies the meaning of health equity, as WHO (2021b) deemed that “no one is safe until everyone is safe” (p. 1). A nursing call to action to promote equity in the face of the pandemic, and a looming shortage of health human resources, was a primary theme at the 2021 Congress of the International Council of Nurses (Chiu et al., 2022, in press). What we are witnessing is a convergence of calls for nursing influence on health equity within global systems that must be addressed not only by individual nurse leaders, but also by a powerful and morally committed nursing profession (Duncan, 2023).

With the exception of the Canadian Federation of Nurses Unions (2021), at the time of writing, we have seen relative silence on this issue from Canadian nursing organizations.
In Canada, the ethical imperative for nursing is exemplified in recently exposed instances of racist practices and attitudes among nurses in the treatment and care of Indigenous people. These instances have contributed to the critique of accounts of historical colonial influences in the development of the profession. This awareness has been growing among Canadian nurses, with recent high-profile events resulting in advocacy and declarations against anti-Indigenous and anti-Black racism in nursing and health care adopted by the Canadian Nurses Association (CNA, 2020a) and the Canadian Association of Schools of Nursing (CASN) in collaboration with 13 other nursing organizations (CASN et al., 2020).

Several accounts of racism in health care have been amplified in the media, including the blatantly racist and harmful treatment by nurses of an Indigenous woman, Joyce Echaquan, while she was a patient in the province of Quebec, Canada (CNA, 2020b). This was a stunning and pivotal moment for Canadians, and for nurses in Canada, to reflect on and accept the reality and trauma of racism, from which the profession of nursing is not exempt. National organizations including the CNA, in collaboration with the Canadian Indigenous Nurses Association (CINA) and other provincial and national organizations, initiated a call to action for “individual and systemic actions needed to decolonize the structures that impact the education, regulation and practice of the nursing profession and ensure that it can provide safe, compassionate and ethical care to all people living in Canada” (CNA [2020a], p. 2). The call for nurse leaders to counter racism and initiate decolonization is not new; rather, it is pervasive and ubiquitous to contemporary practice and must be seen as a central ethical commitment of all nurses (Crowchild & Varcoe, 2021). In coming years, it will be critical to monitor events and progress by nurse leaders for countering these influences on care and health. Such attention is particularly necessary in light of various national inquiries and calls to action with direct implications for the nursing profession (Truth and Reconciliation Commission of Canada Calls to Action, 2015). This social and political moment is indeed a clarion call for ethical nursing leadership.

Nursing calls to action within organizations and systems have been, for the most part, unheeded in recent times, although the measures they encourage have been vital to the safety of patients,
nurses, and the overall health of communities and populations (Bourgeault, 2021; Buchan et al., 2022). Calls to action over past decades have included recommendations to strengthen nursing leadership in practice settings and at senior levels of organizations and the health care system overall to increase opportunities for nurses to have voice and influence in health care decision making; and to promote safe and healthy practice environments for all (Canadian Nursing Advisory Committee, 2002; Duncan et al., 2014).

As a result of the above, questions arise: Why have these challenges been so difficult to address, or ignored, over the past few decades? What does that say about nursing leadership? In answering these questions, we will argue that individual nurses and the nursing profession must engage with new understandings and narratives of power—both in relationships and in the capacity for ethical leadership. Barbara Stilwell (2021) proposed, in her address to the International Collaboration of Community Health Nursing Research, that we embrace power not just as a noun, but in its more active, verbal form: “to power.” This means, in our view, that ethical leadership in nursing must be further conceptualized and realized as the imperative of nurse leaders in interaction with the values of the profession. A new narrative of power is required.

**Contexts and Concepts of Ethical Leadership**

Nurses take on leadership in diverse informal and formal roles. They advocate for standards of practice and serve on committees at various levels of organizations, from the point of care in health care settings to working with communities on directions for health and health care. Nurses who assume formal leadership roles are accountable for strategic influence, vision, climate, and quality in health systems. Formal leadership roles commonly assumed by nurses include practice leads and coordinators; program leads; and executive leads in health care organizations, nursing organizations, and governments. In 1994, Storch identified the levels of influence and accountabilities in nursing ethics at the micro level (individual point of care), at the meso level (organizational), and at the macro level (larger systems). Nursing leadership at the macro level is particularly critical to safeguard and advance ethical practice.
Nursing leaders who are required to shape organizations and systems face considerable challenges. For one, contemporary health systems are most often identified as program-related, with responsibilities that span nursing and other allied health professionals and programs. It is increasingly rare that nursing leadership positions are created where nurses are able to focus primarily on nursing issues and advancements. While we recognize the imperative of interprofessional practice and leadership within nursing, the absence of a dedicated focus on nursing per se creates a void in nursing leadership capacity. There has been some critique of interprofessional discourse with respect to a shift in managerial emphases on other professions or allied health disciplines, while nursing as a discipline and a profession may become less distinct and less represented in leadership (Duncan et al., 2014).

When we consider leadership at the meso and macro levels, there are accountabilities for creating a moral climate in health care wherein nurses and others are able to practice according to ethical values. Therefore, a central feature of ethical leadership is to create and nurture health care environments as moral communities (Austin, 2007), wherein there is constant attention to everyday ethics, and where nurses and others in health care teams and communities come together in reflection and dialogue over pressing moral dilemmas and tensions (CNA, 2017). The extension of a moral community to one that nurtures and supports each nurse, including nurse leaders, is an ethical responsibility for all nurses in the context of growing concerns about bullying and lateral violence (O’Flynn-Magee et al., 2021).

The essence of ethical nursing leadership is to lead in the development of moral communities through reflection on the ethics of everyday practice (Austin, 2007). As Austin suggested, “being ethical is never something that one possesses, it is the recognition of the messy and expanding interdependence of decisions, interests, and persons” (p. 85). Scholars in nursing ethics point to the need for nurses to be more involved in policy development and governance. Yet, an increased focus on managerialism limits the capacity of nurses to lead in the creation of moral health care communities for just and equitable systems of nursing and health care (Aroskar et al., 2004; Austin 2011; Shannon & French, 2005; Storch et al., 2013).
These critical insights have been articulated in the 2017 CNA Code of Ethics for Registered Nurses.

Canadian scholars and researchers in nursing ethics have investigated systemic and organizational influences on the enactment of ethical leadership (Rodney et al., 2002). Storch et al. (2009) led a national study into “leadership for ethical policy and practice” (p. 68). This participatory action research initiative included nurses from diverse walks of nursing—including academic, practice, and organizational leaders—to discern policy actions to improve the ethical climate in health care settings where nurses practice. Participants were offered opportunities for continuous reflection and discussion of ethical issues in everyday nursing practice, and the active listening presence of senior nursing leaders (Storch et al., 2009). Canadian nurse theorists Doane and Varcoe (2021) further contributed to the conceptual landscape of ethical nursing leadership using a relational inquiry lens to review the actions and behaviours of “nursing leadership in every moment of practice” (p. 402).

In addition, research conducted by international scholars Zhang et al. (2021) in a study of 525 Chinese nurses in 65 diverse tertiary hospital departments enriched our understanding of the relationship between ethical nursing leadership and nurses’ capacities for moral reflection and sensitivity at the point of care. Through structural equation modelling, these researchers demonstrated the mediating variable of ethical climate in the relationship between ethical leadership and nurses’ moral capacities at point of care. At the core of moral sensitivity was the individual nurse’s ability to reflect on and identify the fundamental ethical components of situations and actions. Zhang et al. demonstrated how ethical leadership was essential in establishing moral climates to ensure ethical nursing practice for all.

Research conducted by members of other disciplines, both in Canada and internationally, also informs our understanding of dimensions of ethical nursing leadership. For instance, in Canada, feminist researchers extended applications of feminist and relational ethics principles into health leadership contexts. These principles are essential to navigating areas of conflict, as well as values in tension and power (Sherwin & Stockdale, 2017). Public health ethicists provide essential insights into organizational and
societal determinants of ethical leadership. They emphasize the imperative to address social justice by considering the relationship between the good of the individual and that of the collective (Baylis et al., 2008; Upshur, 2002). Ko et al. (2018) conducted an integrative review of research on ethical leadership in other disciplines and countries that added to the understanding of the dimensions of a moral climate within organizations and systems. These researchers offered evidence that qualities such as upholding and enacting codes of ethics and actively voicing concerns about unethical behaviours at all levels of organizations and systems are central to leadership, as is the importance of role modelling consistent ethical behaviours in relationships and advocacy. Signs of a management climate bound by codes of ethics and standards include capacities for whistleblowing among followers, team cohesion, and voicing concerns as a group (Ko et al., 2018).

While these signs represent a flourishing moral climate, they are currently not abundant in nursing and health systems. Increasingly, nurses as individuals, including those in formal senior organizational positions, are not free to speak out on the fundamental issues at the heart of nurses’ moral practice (Newton et al., 2012). The silencing of a strong nursing voice in the public arena, with respect to the expertise of nurses to lead in patient care and health systems, has also been pervasive during the pandemic (Pringle, 2021). Factors contributing to the silencing of the nursing profession, albeit complex, must be fully understood and reconciled.

Enacting the ethical dimensions of nursing leadership has always been challenging. These challenges persist despite years of tracking the impact of neoliberal ideology and managerialism on nursing practice and the profession as a whole (Austin, 2011; Duncan et al., 2014; Kirkham & Browne, 2006). Managerialism in health care and nursing systems is expressed in values of efficiency, and in the dominance of market analyses and forces that determine administrative structures and program outcomes often directed at rationing essential services (Newham & Hewison, 2021; Traynor, 1999). Managerial influences are seen in the introduction of professional managers, those with educational preparation in business, as the way to advance health systems. This trend is detrimental to the full engagement of nurses, and the profession of nursing, in
managing and leading according to professional values and standards (Shannon & French, 2005). Over several decades, this movement has also resulted in changes in leadership in the practice setting, including a loss of nursing management and leadership roles at the point of care, along with promoting the educational preparation of nurses with business degrees for leadership roles. Nurses in most health systems of today experience a disconnection between their practice as leaders and the values and directions of administrative and governance structures. If nurses are present at all in these structures, they are often there to represent a myriad of portfolios and issues that may or may not include the practice of nursing (Storch et al., 2013). As a result, many are unable to confront these managerial forces at the point of care or at the most senior executive levels of those organizations, where nurses constitute the majority of members.

Recently, theorists in nursing and management have been confronting the binary of management and professionalism, and are calling for new understandings and models where professional identities and values are realized within management systems (Mintzberg, 2017; Newham & Hewison, 2021; Noordegraaff, 2015). This includes an awareness that management and nursing leadership coexist; nurses who are managing teams, programs, or organizations have critical skills, knowledge, and ways of being to bring to these roles. For example, Mintzberg (2017) recognized the former leadership and management roles of head nurses as highly valued because of their intimate engagement with practice; their knowledge of the immediate day-to-day contexts of nursing practice; and their relationships and presence with nurses, patients, and others.

In our critique of managerial influences on health systems, and on the nursing profession and the enactment of ethical leadership, we distinguish between management and managerialism. Nursing management is a component of leadership required to shape and lead systems of care, while managerialism is an ideology that has transformed how management is enacted in public systems (Carroll & Shaw, 2001; Traynor, 1999). In order to navigate competing ideologies, nurse leaders must expand their critical awareness of managerialism and its impact on their capacity to enact ethical leadership. This requires a constant interaction with power in
relationships, including the development of ways to bring people and organizations together. The values of the nursing profession are instrumental to enacting ethical leadership. This requires the strength, vision, and strategic influence of the profession itself (Myrick & Pepin, 2019). At the same time, we are witnessing the erosion of the power of professional nursing associations with respect to advocacy for nursing values, issues, and dissenting views.

Ethical leadership in nursing is supported by philosophical perspectives, including critical and feminist world views, and, as developed by nurse scholars, a perspective on feminist relational ethics and Indigenous cultural understandings (Bergum, 2013; Bourque Bearskin, 2011; Doane & Varcoe, 2021). Feminist theorists view relational theory in ethics as a means of addressing global issues and helping to build communities for social justice (Sherwin & Stockdale, 2017). Relational and communitarian perspectives inspire the call to action for nurses to act globally to create universal health access. Together, these perspectives encompass the critical view of power in relationships and the call to build relationships across difference while leading according to professional values.

Ethical leadership also means advocating for policy agendas that align with the profession and nursing codes of ethics. Policy advocacy may be viewed as leadership ethics in action, and requires new theoretical and methodological perspectives (Chiu, 2020). For example, in examining theories for advancing policy advocacy in nursing, Chiu observed that ethical knowing is not only integral to policy advocacy; an ethical perspective is core to social justice and equity values and commitments. Such attentiveness to ethical knowing also extends to policy solutions for social change. Nurses leading systems and organizations are calling for principled action in reforming community-based systems of care, which have been given short shrift in current times (Caxaj et al., 2020; Lefebre et al., 2020). It is also incumbent on nursing organizations to base policies and positions on the ethics and principles of the profession (Copeland, 2020). Ethical inquiry into situations where leaders have successfully advocated for professional values and practice standards provides insights into how leadership can be supported and enacted in present day challenges, as the following exemplar illustrates.
**Historic Exemplar of Ethical Nursing Leadership: “I Care That VGH Nurses Care”**

This exemplar of nurses confronting the Vancouver General Hospital (VGH) bureaucracy was highly visible over four decades ago in media and public arenas. However, few public records or publications have emerged; those which are known to exist are less accessible due to the loss of nursing archives. It is fortunate that Verna Lovell (1981), a nurse and sociologist, was able to document the entire situation. She published a rigorous analysis of what transpired in a case study titled “I care that VGH nurses care!” This publication is, to our knowledge, one of the few exemplars of meso level organizational nursing leaders standing together in the corridors of power of a large health care organization in order to enact essential improvements in patient safety and nursing practice. We contend that the case study has relevance to nursing today and provides useful ethical insights for nursing leaders.

Of note in this leadership scenario is the courage exercised by nurses in leadership positions—including the clinical directors of surgical nursing, medical nursing, psychiatric nursing, and obstetrical and gynecological nursing, in taking a stand for patient care. These nurse leaders resigned from their positions in opposition to the failure of the VGH board of trustees and the senior executive team to hear growing concerns about the safety of patient care across the institution. Several head nurses followed suit.

The Director of Nursing, Mary Richmond, resigned in December of 1973, after “she was unable to make changes she regarded essential” (Lovell, 1981, p. 26). A new operational plan for VGH was conceived shortly after Richmond’s departure, and nurses did not have a say in the appointment of her successor. This became a central issue in the dispute. The remaining nurses stood together and focused their advocacy on patient care. They formed the Committee of Concerned Nurses, which engaged hundreds of nurses in public awareness campaigns and assemblies. The group used established channels within the organization and government to present documented incidences of compromised patient care standards. When the nurses’ concerns fell on the deaf ears of senior
executives and government officials, they effectively engaged the public through the media.

In her analysis of the power dynamics between the nurses and the VGH president and board of trustees, Lovell (1981) sheds light on the means of “coercive control” leveraged against the Committee of Concerned Nurses. She suggests that VGH’s managerial reaction was punitive because the Committee challenged “the normative order” and “by virtue of its very existence, was considered deviant” (p. 40). Control measures ranged from “failing to regard as legitimate” the claims of the nurses, to “scolding,” “shaming,” “intimidation,” and “censuring” them, and “praising” those who “told the other side of the story” from what the Committee presented (Lovell, pp. 40–43). Descriptions and evidence of how these control measures were manifest is likely one of the most significant exposés of a narrative of power that has persisted in the world of nursing, and one that must be confronted today.

The efforts and stance of the nurse leaders garnered the support of other organizations, including professional associations of the day—the Registered Nurses Association of British Columbia (RNABC), the Canadian Nurses Association, the International Council of Nurses (ICN), the BC Association of Social Workers, the faculty of the University of British Columbia, and others. The core group communicated with the Canadian Council on Hospital Accreditation and challenged VGH’s accreditation because of a lack of nursing positions and unsafe staffing levels.

Of particular note was the role and contribution of the RNABC. This professional association provided immense operational support for organizing and communicating concerns, as well as political influence, by bringing the voice of the nursing profession, including its standards and ethics, to the fore. Also noteworthy is the connection and commitment of the RNABC to advocacy efforts in the interest of patient safety. The RNABC had, in the fall of 1976, established a “Safety to Practice Program” which was supported by a resolution in 1976: “That RNABC place increasing emphasis on assisting members to take effective action to ensure that the settings in which they practice make competence possible” (RNABC, 1976, p. 4). This in itself is a powerful reminder of the need to act together as a profession in the interest of patient safety through advocacy and
courage in leadership at a systems level. It is of concern that this level of attention to systemic influences on patient safety seems absent in today’s arena of evolving nursing organizations and their respective mandates for regulation and professional practice standards.

**REFLECTIVE QUESTIONS**

1. *How does the exemplar of nursing leadership at the Vancouver General Hospital resonate with the contexts and challenges of today?*

2. *Was ethical leadership enacted in this situation? What characteristics stand out?*

3. *What are the implications of this situation and the narratives of power it represents for ethical nursing leadership today?*

**Codes of Ethics: The Nursing Profession as a Moral Community**

We now turn to the exploration of how codes of ethics inform and support nursing leaders in organizations, and societal contexts. The values of the nursing profession in Canada are articulated in the Canadian Nurses Association’s (CNA) *Code of Ethics for Registered Nurses* (2017), and globally, in the recently revised International Council of Nurses’ (ICN) *Code of Ethics for Nurses* (2021c). The CNA recognizes the need for nurses, regardless of position, to continuously reflect on how they are enacting their ethical commitment to practice and to the persons, families, and communities they serve. Today, these pressing moral concerns are constant in the face of limited nursing resources, pandemic challenges, and racism in practice environments. However, it is important to acknowledge that along with these challenges are unlimited possibilities for elevating the moral climate of all communities; this is envisioned as a primary nursing leadership role in enacting “everyday ethics.”

The 2017 CNA *Code of Ethics* refers to the issue of power and the need to recognize and attend to “power differentials among formal leaders, colleagues and students” (p. 13). Further, the 2017 CNA *Code of Ethics* addresses the principles of justice as they pertain to the recognition and respect of Indigenous-specific history and inter-
ests, including direct reference to the requirement that nurses do not discriminate. The 2017 version of the CNA *Code of Ethics* does not explicitly refer to the issues of colonization and racism; however, it is likely that the next version will be extended to recognize the evolution of thought and commitment in the nursing profession in Canada. In addition, the 2017 CNA *Code of Ethics* includes visionary direction for leadership and action during pandemics, and in those instances where nurses must take action to address unsafe or unethical care. These scenarios have increasing relevance in the contemporary leadership context.

A revised edition of the ICN *Code of Ethics* was released at the 2021 ICN Congress. Highly relevant to framing nursing leadership at the level of the profession, this revised code of ethics emphasizes the integral role of the professional nursing association in establishing wide-ranging ethical accountabilities for safe and high quality practice and health systems. The relationship between nurses and the profession features prominently in this revision. This emphasis extends to nursing leaders in the creation of roles, relationships, and directions for nursing organizations as they evolve with disparate and sometimes competitive mandates. It is essential for nurse leaders to ensure that organizations governing or regulating nursing practice uphold the values of the profession. It is incumbent on nurse leaders to “promote participation in national nurses’ associations to create solidarity and cooperation to promote favourable socioeconomic conditions for nurses” (ICN, 2021c, p. 16). In summary, authors of nursing codes of ethics are clear in calling for nurses to engage in new narratives of power by advocating for equity in health and for justice in the human rights issues prominent in the nursing profession itself, including the promotion of ethical nurse recruitment and migration (Buchan et al., 2022).

Nurse leaders in the 21st century require the relational commitments and competence to develop inter-organizational relationships while recognizing disparate agendas and values. Inter-organizational relational competence is particularly relevant in leadership today, and is required among those who hold senior formal positions of leadership in the profession of nursing (ICN, 2021c). Also, in recognition of broad mandates for ethical leadership, The Canadian College of Health Leaders (CCHL) *Code of Ethics*
(2021) outlines the ethical standards pertaining to individual, professional, organizational, and community relationships for health care leaders. The CCHL Code of Ethics specifies the value of collaboration at all levels as essential to fulfilling the social mandate for ethical leadership, once again recognizing the importance of reflection, dialogue, and public participation as essential to leadership in health systems. This view is consistent with nursing codes of ethics in that individual leaders, in their enactment of leadership, must include professional, organizational, and community commitments and relationships. New understandings of ethical leadership, and awareness of responsibilities to build and sustain relationships within and between organizations, are needed. As discussed, codes of ethics provide specific direction for these leadership roles.

**Discord and Discontinuity in Nursing Organizational Mandates**

ICN’s (2019) strategic priorities of the socio-economic welfare of nurses, the profession of nursing, and nursing regulation are conceptualized as three pillars that must work in concert in order for the nursing profession to fulfill its social mandate for global health. Therefore, nurses who lead nursing organizations must commit to these essential mandates at the local, national, and international levels, and they must ensure a level of collaboration that fulfills the synergistic interrelationship of these priorities at operational levels. For instance, as patient safety issues continue to grow, organizations that regulate nursing practice must work synergistically with nursing organizations that promote the advancement of the profession and the socio-economic welfare of nurses. This level of inter-organizational collaboration must occur in order to attend to the systemic influences on patient safety by implementing progressive care delivery models, advocating for resources necessary for safe practice, and ensuring that nurses’ rights to safe and optimal working conditions are upheld (Borgeault, 2021; Traynor et al., 2014).

Despite the recognition of the three pillars as a unifying framework, one that has served the nursing profession and the public for over a century, there is an unfortunate, growing disconnection between nursing organizations as they evolve with
separate mandates (Duncan et al., 2015). As a result, nursing organizations have lost some important connections with each other and with nurses. These disconnections have reduced the capacity of the profession to speak, influence, and advocate for health systems and conditions of health equity. In fact, individual nurses’ levels of engagement with the profession itself is in peril, as membership models are threatened while regulatory systems become increasingly focused on a single mandate of regulation and increasingly divorced from professional self-governance as a guiding principle (Duncan & Whyte, 2018).

Nursing organizations in Canada have evolved over the past fifteen years (Whyte & Duncan, 2017). In 2021, a landmark change in the constitution of the CNA resulted in the loss of a century-old membership model for provincial and territorial associations. The model had ensured a connection between nurses across the country, and was part of nurse registration (Villeneuve & Guest, 2021). This recent change challenges the strength and viability of a unified national voice for nurses in Canada through the CNA, and their connection to the global nursing community through the ICN. The full implications of these changes for the nursing profession and those it serves have yet to be fully recognized and critically examined in Canada and beyond. The moral community of the nursing profession is enacted through formal, integrated, and collaborative networks and organizations committed to the values of the profession. In light of discord among nursing organizations, we challenge the emerging and narrow vision of regulated nursing practice when it is seen in disconnection from the mandate of professional associations. The challenge is to launch a rigorous research program about the impact of emerging regulatory systems on the profession of nursing and its capacity for safe and quality patient care.

Finally, we observe that Part II of the 2017 CNA Code of Ethics constitutes the essence of ethical nursing leadership, as it identifies “ethical endeavours related to broad societal issues” (p. 18). Yet, it also identifies these essential aspects of ethical nursing leadership as outside of regulated nursing practice. Given the call to address broad societal influences on equity, racism, and human rights—and their integral relationship with safe and ethical nursing practice—
we contend that this exclusion from what it is considered “regulatory” in nature must be critically and urgently re-examined. We argue that this exclusion of social justice and advocacy from regulated and accountable nursing practice lacks congruence with the conceptualization and enactment of ethical nursing leadership. This is, therefore, an area in which the nursing profession could lead change and transformation—in determining what constitutes ethical nursing practice by ensuring that future revisions of codes of ethics represent the social justice issues of our time. It is essential that codes of ethics are not narrowly conceived as regulatory instruments; codes of ethics for nursing must be supported by a nursing profession engaged and invested in ethical leadership in all realms of nursing practice, including advocacy for the promotion of social justice and health equity.

Cases of Ethical Nursing Leadership

To highlight and reflect on contemporary ethical challenges, three cases involving nurses working in advanced practice and leadership roles at meso and macro levels of health care and political systems are presented. The capacity for reflection is foundational to nursing ethics, and for leaders, these reflections must extend to organizational and global contexts. Reflection on values in tensions, differences, and narratives of power must be pursued for deeper understandings. We offer a series of questions to guide inquiry into these cases, and we suggest ethical models for reflection, including those appended in the 2017 CNA Code of Ethics and others described in Chapter 1 of this book. These models can be used by advanced practice nurses and leaders for ethical reflection that guides analyses of goals, relationships, values, and decision making. Such analyses can be extended to community and systemic levels, providing emerging insights for leaders and organizations. In Ethics in Practice 7-1 below, as you read the scenario, imagine that “you” are the Chief Nurse Executive in a Canadian health region.
In my role as Chief Nurse Executive in a Canadian health region, it is my privilege to represent nurses and other allied health professionals at the most senior executive level of a health authority in a large urban centre. My commitment in this leadership role is to enact participatory leadership by connecting and listening to nurses across the organization about their issues and pressing concerns. In recent years, I have advocated for nursing knowledge and advancements in professional practice.

In this role, I also bear witness to the erosion of nursing human resources with the loss of roles such as advanced practice nurses and clinical nurse specialists. Under the guise of an intent to “recognize scopes of practice,” this erosion and loss of advanced practice leadership results in the shifting of tasks among categories of nurses and health care attendants without due consideration of the implications for roles, unique contributions, and leadership within a team. I recognize that these trends prevail across the system of acute institutional care, long-term care, home care, and public health settings of care. Introduction of new care delivery models is at times advocated for and supported by nurses in managerial positions who seek to maximize efficiencies. Further, human resource allocations are made without due consultation with nurses, review of literature, or evidence and evaluation frameworks that identify impacts on care and health outcomes, including but not limited to the safety of patients and nurses.

As the most senior leader with a nursing portfolio, I am morally compelled to address issues that are adversely influencing nurses and nursing practice across the organization, and to bring awareness and strategy to the most senior levels of the organization. My actions include tabling issues related to nursing practice concerns, proposed strategies, and evaluation by the senior executive team. These actions are often met with the response: “You are too focused on nursing, and you must take a broader view of other health team members and issues across the organization in order to lead effectively.” The implication of this response, which is common discourse, is that leaders who bring nursing-specific issues to the fore are inwardly focused on serving the nursing profession over broad health care delivery issues and concerns.

In discussion with other nurses in positions such as mine, I recognize that this situation is not unique: the lack of focus on nursing and its priorities is prevalent in health organizations. As a group of nurses with a mandate to represent nursing at senior levels of organizations, we lack a professional forum for reflecting on and addressing the day-to-day ethical issues in nursing practice, the profession, and standards of safe practice. We recognize the growing urgency and intensity of nursing issues during the COVID-19 and opioid pandemics, and how the sustainability of the future nursing workforce must be supported with evidence-informed policy solutions.
As leaders, we do not always agree on a course of action—whether it is best to confront issues and bring strategies for change, or uphold institutional directions and not “rock the boat.” Through further discussion, we also recognize that regulatory organizations in nursing no longer take a systems view on professional practice, and that new forms of professional organizations are emerging. However, the influence of these factors on everyday ethics and professional practice and leadership is unknown at this time. Equally distressing is our lack of opportunity to engage others in the organizations, including nurses in senior management positions and government, in reflection, dialogue, focus, and change.

**REFLECTIVE QUESTIONS**

1. **What would constitute ethical leadership in this situation?**

2. **What roles do nurses in formal leadership positions at micro, meso, and macro levels play in making decisions about care delivery models, and how do they enact ethical leadership in these situations?**

3. **What is the role of the nursing profession in enacting ethical leadership, and what directions do codes of ethics provide?**

4. **What perspectives and values best inform ethical nursing leadership in this instance?**

* To read more about the opioid crisis, please see Chapters 9 and 10 in this textbook.

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**ETHICS IN PRACTICE 7-2**

*Advocacy for Global Equity: The Voice of the Nursing Profession*

Since the COVID-19 pandemic began unfolding early in 2020, there has been a growing recognition of the equity issues in nursing and health systems in Canada and globally. Nurses responsible for staffing are charged with recruiting more nurses from less well-resourced countries in order to meet current demands. At the same time, there is an emphasis on securing vaccine supplies that will protect all Canadians, including children, with primary series and boosters. Along with the rise of the sixth wave of the Omicron variant of concern in Canada is the recognition of the issue of global vaccine equity: “No one is safe until everyone is safe” (WHO, 2021b, p. 1). The World Health Organization has launched a campaign for vaccine equity, noting achievable strategies
through sharing vaccines, resources, and intellectual knowledge for sustainable production of what is needed in countries across the globe.

A team of APNs in a public health unit charged with coordinating the local response to the pandemic in a large urban centre in Canada notes the lack of a professional nursing voice on the equity issues associated with the experience of the pandemic. They are also aware of how public health nurses and nursing students are witnessing inequities in care and health during the pandemic and experiencing moral distress (Wros et al., 2021). Nurse leaders are troubled with this lack of nursing advocacy at a time when the profession lays claim to holding values and principles of social justice and equity.

One of the nurses attends the 2021 ICN Congress, where there is widespread attention on the injustices inherent in nursing recruitment, mobility, and access to vaccines and treatments specific to the pandemic (ICN, 2021a). The nurse conveys this perspective to other public health nurses and asks why these issues are not exposed in the profession and society at large. Collectively, the nurses discuss ways to promote awareness and reflection on the responsibilities of the profession to provide leadership for equitable and evidence-informed solutions to sustaining a global nursing workforce. They consult international policy documents that clearly outline the ethical issues associated with nurse migration and sustaining and retaining nurses (Buchan et al., 2022).

**REFLECTIVE QUESTIONS**

1. **What would constitute ethical leadership in this situation?**

2. **What resources might advanced practice nurses draw upon to inform ethical leadership in these situations?**

3. **What is the role of the nursing profession, and how can it support ethical leadership for global health equity?**

4. **What perspectives and values best inform ethical nursing leadership in this instance?**

* See WHO (n.d.).
ETHICS IN PRACTICE 7-3

The Future of Nursing Education

As chairperson of a Bachelor of Science in Nursing (BScN) program in a Canadian university, I am approached by government policy officials in the ministries of health and advanced education to increase nursing program enrolments by 25% in order to respond to the growing shortage of nurses. In addition, the provincial government is recommending implementation of a nursing program that is reduced in length and focused on immediate and visible staffing challenges, primarily in highly acute critical and surgical areas. University administration is aware of issues that could arise from these suggestions for change to the nursing program; however, they wish to respond to government requests and, therefore, want to increase nursing seats in the BScN program. The administration also supports my advocacy for increased graduate enrolment to prepare faculty and researchers.

As I think through options and potential responses to university and government leaders, I am approached by faculty and students who have heard about these changes. They are concerned about having fewer faculty to teach students; reduced capacities for practice placements in all areas of the health system; existing nurse staffing challenges; and student and patient safety. We also realize that the proposed program changes will not prepare students to (a) lead programs of care in primary and community health settings; (b) adopt a critical lens on power and technologies; or (c) lead for culturally safe systems of care.

I am a member of a council of nursing education leaders in one Canadian province where I hear the same concerns raised by colleagues. At a recent meeting of the council, leaders from member schools of nursing discussed the warning issued by the Canadian Association of Schools of Nursing (2021), that nurses will not be adequately prepared in shorter, less rigorous nursing education programs. Further, a policy brief by the ICN (2021b) calls for global investments in nursing education—including providing financial support for students and increasing the faculty complement—as progressive and visionary strategies for ensuring a well-prepared nursing program.

As nursing education leaders, we recognize that the shortage of nurses, including nursing faculty, has been predicted for decades and exacerbated by the pandemic. This shortage has resulted in a priority being set, with nursing education receiving an unprecedented amount of attention from policymakers. This immediate and urgent attention to policy in nursing education by governments, health, and educational institutions raises questions of how nursing education leaders can, and must, influence the future directions in nursing programs and curricula that will determine the care and health of populations for decades to come. We weigh the options while recognizing our roles as employees of educational institutions with immediate accountabilities to government for enrolments and graduations.
Conclusion: On the Horizon of Ethical Nursing Leadership

In conclusion, we return to the question we posed in the introduction to this chapter: How do we envision ethical nursing leadership as enacted by the individual nurse leader in concert with the nursing profession as a whole? As we have theorized in this chapter, the relationship between leaders and the profession must be strong when facing health challenges and opportunities. As custodians of the nursing profession, leaders must acknowledge the moral courage and tenacity of nurses in the evolution of the discipline and profession of nursing. Virtues such as courage and integrity in upholding professional nursing values are required to enact ethical nurse leadership, as recounted in the cases presented in this chapter. We focused particularly on the historic case of nursing leadership at the Vancouver General Hospital in 1978, amidst the earliest appearances of what came to be recognized as managerialism in health care systems. This exemplar of nurses advocating for nursing issues and patient safety indicates how leaders gain power and influence through engagement with the knowledge, standards and codes of ethics, and relational strengths of the nursing profession.

Nurse leaders and their respective communities, at all levels of organizations, must lead with world views that transform and sustain respectful participatory systems where nurses and those they serve have voice and influence. To these ends, nurses must consider diverse ideologies and adopt critical perspectives and

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<td>1. What would constitute ethical leadership in this situation?</td>
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<td>2. What resources are available to support advocacy for nursing education standards and quality?</td>
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<td>3. What is the role of the nursing profession in enacting ethical leadership?</td>
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<td>4. What perspectives and values best inform ethical nursing leadership in this instance?</td>
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strategies for countering the influences of managerialism on their values and leadership. Drawing upon these perspectives will enable nurses to consider other world views in order to inform new ways of being in a changing world (Chinn, 2013; Crowchild & Varcoe, 2021; Doane & Varcoe, 2021; Rich, 2007).

Further, the profession must grapple with the contemporary challenges of preparing and supporting nurse leaders with courage and commitment to honour the values of the profession and global calls to action. This means that creating spaces for dialogue and building relationships in order to reach across differences—at individual, organizational, professional, and community levels—are foundational accountabilities in ethical nursing leadership. As described in the VGH exemplar, nurses at VGH were skilled in communicating patient safety and nursing practice issues in the public sphere. It is essential that nurses in all roles, including students, develop the capacity for voice and influence in various forms of media communications in order to articulate and expand awareness of complex ethical issues. These competencies must be taught, practiced, and supported (Buresh & Gordon, 2000).

Calls for nurse leaders to lead ethically are clearly focused on valuing and engaging nurses in voice and influence, creating a participatory culture in order to ensure sustainability of the professional values and ethics in morally dynamic systems of care. A new narrative of power is required as the profession critically examines how it enacts its values and relationships within the global community of nurses. For example, our [Duncan’s and Newton’s] graduate students in nursing have told us how their nurse leaders demonstrated compassion for both nurses and patients during the difficult months of the COVID-19 pandemic. These same nurse leaders now need communities of compassion for themselves in the long road to build systems of care and extend a vision for renewal of care delivery. Relational leadership, rooted in feminist and critical philosophies, underpins values required to develop moral communities of influence (Chinn, 2013). Feminist understandings inspire collectivity and capacity for nurses to lead organizations with a spirit of creating space and respect for diverse mandates (Bergum, 2013; Sherwin and Stockdale, 2017). Further, Indigenous perspectives inspire leaders to create space for reconciliation and
anti-racism (Ermine, 2007). Indeed, there is a call to action for nurse leaders in Canada to lead in the anti-racist movements and decolonization of nursing and health systems (Bourque Bearskin, 2011; Crowchild & Varcoe, 2021).

Finally, leaders of nursing organizations, in particular, must create space for dialogue and ethical discernment among regulatory, professional, and union mandates. Otherwise, fragmentation and loss of voice and influence within the nursing profession—with attendant blows to nurses’ capacities to live their values—will continue. At stake is the power and moral agency of nurses, who are an urgently needed, essential global force for achieving the most profound and pivotal health goals for the future.

**QUESTIONS FOR REFLECTION**

1. *Discuss the meaning of a new narrative of power in ethical nursing leadership. How might this new narrative serve to counter managerial ideologies in health care systems?*

2. *What are the exemplary features of nursing organizations required to support ethical nursing leadership in health systems and organizations? What will this require of leaders of these present-day nursing organizations?*

3. *APNs are accountable for negotiating ethical challenges that arise with a focus on both patients/populations as well as the system within which they are embedded. What supports are required to enact their moral agency as APNs to attend to such responsibilities? How can APNs balance these (sometimes) competing priorities while also advocating for nurses and the creation of a mutually supportive community?*

4. *Canada has recently hired a Nursing Officer in the federal government with the accountabilities for establishing a vision of leadership and policy influence for nursing in the country (CNA, 2022). How would you advise this most senior nurse to build capacities for the ethical nursing leadership required to sustain and strengthen the profession and develop capacity within governments?*

5. *What research agendas are required to inform ethical nursing leadership in the next decade?*

6. *How can the nursing profession as a moral community nurture and support its leaders in building a community of dialogue and respect among nurses in relationship?*
Endnotes

1 See Chapter 20 in this textbook for more on Global Health.

References


Chapter 7: Ethical Leadership


Toward a Moral Horizon


SECTION 2

Pursuing Equity in Diverse Populations
“The Courage to Teach is for teachers who have good days and bad, and whose bad days bring the suffering that comes only from something one loves. It is for teachers who refuse to harden their hearts because they love learners, learning, and the teaching life. When you love your work that much—and many teachers do—the only way to get out of trouble is to go deeper in. We must enter, not evade, the tangles of teaching so we can understand them better and negotiate them with more grace, not only to guard our own spirits but also to serve our learners well.” (Palmer, 1998, pp. 1–2)
FOR THE AUTHORS OF THIS CHAPTER, all of whom have engaged in advanced nursing practice as educators and leaders, the words of Parker Palmer are meaningful. Having the courage to teach, and to do so ethically, is at the core of nurse education. In this chapter, we shift the ethical lens from clinical nursing practice to the practice of nursing education; we include the nuances and complexities of ethics in everyday teaching practice and leadership; and we draw on the concept of relational pedagogy, a perspective that nurse educators use to prioritize relationships over individualism. We use ethical decision-making frameworks to provide readers with guidance to enact ethical practice. Throughout this chapter, we acknowledge that nurse educators are advanced practice leaders, as their roles entail significant leadership responsibilities in Canadian health care and education systems.

Contemporary nursing education is an ethical practice (Ehrich et al., 2011), grounded in principles of social justice, safe, competent practice, and relational pedagogy (Bergum, 2003; Canadian Nurses Association, 2017; Hartrick Doane & Varcoe, 2015; Osman & Hornsby, 2017). Nursing education is also embedded in a labyrinth of neoliberalism (Darbyshire & Thompson, 2021; Goodman, 2014; Grant, 2014; Osman & Hornsby, 2017; Snee et al., 2021), including the corporatization of higher education (Rolfe, 2019), a severe shortage of nurses (Snee et al., 2021), and resource scarcity (Emanuel et al., 2020).

Nurses and nurse educators are among the most significant scarce human resources in health care. Currently, nurses are positioned as “heroes” as a way of rhetorically masking the many systemic resource failures during the COVID-19 worldwide pandemic (Einboden, 2020). In 2021, the British Columbia Nurses’ Union stated: “[O]ur health-care system doesn’t need more heroes. We need more nurses.” Leaving aside the problematic nature of the hero label, it is notable that nurse educators were rarely acknowledged as heroes during the global pandemic, despite their considerable efforts to ensure that learners’ education would continue as seamlessly as possible (Poindexter, 2021).

Nurse educators provide leadership in complex and diverse environments that present both challenges and opportunities regarding ethical practice. For example, in Cotter and Clukey’s
(2019) study of the cultural context of academic nurse educators, faculty described their interactions as “guarded, uncivil, and conflict avoidant within a bureaucracy of slow pace of work, resistance to change, heavy workloads, and requirements for scholarship that are not clear or consistently enforced” (p. 139). In addition, nurse scholars are critiquing academic scholarship as unchallenged dominant discourses and power structures that have supported Western, colonial, and gendered thinking above other forms of knowledge (Crosschild et al., 2021). In this milieu, what is valued is linked to problematic power dynamics, within a Western paradigm in which empirical knowing is respected over other ways of knowing such as “Black feminist ways of thinking and Indigenous cosmologies and epistemologies” (Crosschild et al., 2021, p. 3).

Overall, the proliferation of adherents of neoliberalism undermines critical scholarship. As Canadian nursing leader Michael Villeneuve (2017) notes, neoliberalism is a prominent and pervasive political ideology “where policies often tend to favour market forces and privatization” (p. 24). Neoliberalism has therefore become linked to the corporatization of higher education (Grant, 2014). Rolfe (2019) claims that nurse academics are torn between the values of the corporate university and the values of clinical practice; between “giving the customers [learners] what they want in order for them to secure well-paid employment and giving them what they need in order to be caring, compassionate and effective nurses” (p. 7). All of this is to say that academic life is complex and filled with both positive and negative relational, intellectual, and ethical encounters.

**Where Does Ethics Fit in Nursing Education?**

It is imperative to focus a discussion about ethics in nursing education from the level of the individual through to socio-political contexts, due to the importance of social justice as a foundation on which ethical practice is enacted (Hartrick Doane & Varcoe, 2015; Kenny et al., 2010), and the need for nurse educators to engage in a “socially just pedagogy” (Osman & Hornsby, 2017). There are shortcomings in the prevailing individualistic ethics framework (Kenny et al., 2010) which require a recognition of the centrality of relation-
ships in education (Ikpeze, 2018; Zhang, 2021). Relational pedagogy and relational ethics are discussed by some authors at the interpersonal level (Bergum, 2003; Deschenes & Kunyk, 2020; Ikpeze, 2018), and by others more contextually (Aspelin, 2021; Hartrick Doane & Varcoe, 2013, 2015), emphasizing relationships in the socio-political and cultural contexts of education.

Within relational pedagogy, there is an emphasis on the relational space—that is, the space *between* learner and teacher (and others)—where power is enacted by those engaging in relationship (Bergum, 2003). There are varying theoretical perspectives on power, but we focus on relational power as enacted in a *relational space*, where power is shareable and mutually empowering (Qin, 2018). Notably, even though issues of power and hierarchies have long been known to exist in health care, they are seldom analyzed in traditional health care education systems such as nursing or medicine (Halman et al., 2017).

For clarity and inclusivity throughout, we use the terms “learners” to denote graduate and undergraduate students, and nurse learners; and “educators” to denote faculty members, clinical teachers who work with students and/or nurses, patient/client educators, as well as advanced practice nurses and leaders whose roles include education in some form.

### A Call for a Focus on Ethical Concerns Within Nursing Education

While there is much written on ethics in nursing education, authors often focus on the teaching of ethics and teaching for ethical practice (Brown & Allison, 2013; Fowler & Davis, 2013). Little attention has been given to the many ethical concerns within nursing education itself. Fowler and Davis (2013) observe that significant attention is given to nursing education issues related to authorship, such as student cheating, at the expense of other ethical issues that are given little or no focus. For example, it would be rare to see the issue of faculty impairment explored in the nursing literature. These authors go so far as to suggest that “the entire domain of ethics in nursing education is, itself, taboo” (p. 129). As educators, we question why this is so, and ask if it is time to bring the “taboo” out in the
open. A first step is to make visible several relevant questions, including the following, which are related to the Ethics in Practice scenarios we describe in more detail later in the chapter.

1. How might educators enact their moral courage to address an issue with a colleague’s practice that has come to light through a learner’s concern?

2. How can educators respond when academic or clinical practice nurse leaders do not act on concerns, for example, bullying of learners?

3. How can educators and leaders use their collective voices to disrupt socio-political policies and practices that create moral distress for learners and educators, and have the potential to cause harm to health care providers, their clients, and families?

4. How might learners be supported in questioning, and ultimately addressing, a culture of poor practice in various contexts?

When grappling with questions such as these, it is important to uncover the theoretical and ethical guidelines that educators can use to enact their teaching practice at intrapersonal, interpersonal, and contextual levels (Hartrick Doane & Varcoe, 2015).

**Theoretical and Ethical Guidelines for Educators**

In this chapter, we focus on relevant theoretical perspectives in education, grounding our work and practice in critical pedagogy (Freire, 1968/2018). Using a critical approach enables teachers and learners to recognize education as social and political, to examine the effects of power and privilege in health care (Halman, 2017), and to question “what is, why it is so, and whether it must be that way” (Peters & Mathias, 2018, p. 63).

Drawing on the work of Freire, bell hooks (1994) positioned education as an act of freedom, acknowledging the intersections among anticolonial, critical, and feminist pedagogies, and citing the classroom as having the potential to house the most radical space in the academy. hooks (1994) described a pedagogy of engagement as
an inclusive space which is foundational for learning and action to occur. Rather than “safe” space, we use the term “safe(r)” to acknowledge the difficulty of guaranteeing safety for all, recognizing that safe for one may not be safe for another. Educators should strive for space that is as safe as it can be (Anderson & Riley, 2020; Carello & Butler, 2015; Deller, 2019; Mental Health Commission of Canada [MHCC], 2019). Ideally, educators work with learners to co-create a safe(r) educational space where diverse views are welcome, and teaching is action-oriented with the goal of transformative learning (Freire, 1968/2018; hooks, 1994). Educators who promote transformative learning believe in the potential of learners, so that learners can be confident in their own capacities to enact change at the socio-political level (McAllister, 2015). The notion of a socially just pedagogy has been discussed in non-nursing literature as one way to bring higher education back to its roots of social justice (Osman et al., 2018). Transformative learning intersects with socially just pedagogy to foster critique of current pedagogic practices and support educators to strive for education for social change. It asks them to consider “what they teach, how they teach, and why they teach” (Osman & Hornsby, 2017, p. 3, emphasis added).

In Canada, it is especially important that educators dismantle colonial ways of knowing, learning, and teaching (Canel-Çınarbaş & Yohani, 2019; Pidgeon, 2016; Stansfield & Browne, 2013), so that they can honour the 2015 Truth and Reconciliation Commission of Canada: Calls to Action (TRC). For example, call to action 24 states

We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism. (p. 3)

To support nursing educators and academic institutions to take up the TRC (2015) calls to action, the Canadian Association of
Schools of Nursing (CASN, 2020) released a document describing strategies to address Indigenization, decolonization, and reconciliation. Embedded examples within three broad categories—foundational, recruitment, and curricular strategies—include the importance of partnerships, faculty/staff education, designated seats for Indigenous students, hiring and supporting Indigenous educators, and inclusion of Indigenous epistemologies and ways of being in the world.

Indigenization in higher education is complex and must move beyond tokenism to truly embrace Indigenous ways of learning, knowing, and doing (Pidgeon, 2016) to provide more holistic curricula in nursing education (Stansfield & Browne, 2013). This inclusion must be done in respectful partnership with Indigenous Elders and Knowledge Keepers so that there is minimal risk of appropriation or misappropriation of Indigenous Knowledge (Stansfield & Browne, 2013). We posit that by embracing anti-racist curricula and Indigeneity in nursing, educators can support the theoretical and philosophical commitments to ethical nursing education that are described in this chapter.

An Ethical Framework for Nursing Education

It is important for nurse educators to use frameworks to guide their practice. For example, the Society for Teaching and Learning in Higher Education (STLHE), a team of award-winning educators in Canada (Murray et al., 1996), has proposed an ethical framework for education. The STLHE framework has a series of nine principles for teachers in higher education, namely

- competence in content
- competence in pedagogy
- skill at addressing sensitive topics
- commitment to supporting learners’ development
- proficiency at maintaining professional relationships with learners
- confidentiality
- respect for colleagues
• valid and fair evaluation of learners’ work; and
• respect for one’s institution (Murray et al., 1996)

The aforementioned theoretical approaches and ethical principles are, of course, illustrative examples, and readers may have their own tried and trusted approaches (see Appendix 8-1 for an individual exercise to explore what guides your teaching practice). Ethical situations in nursing education are increasingly complex (Rosenkoetter & Milstead, 2010), thus requiring educators to use systematic approaches in order to address them. Ethical frameworks can support understanding and action when educators are faced with an ethically challenging situation. Despite their importance, there is a paucity of ethical frameworks for nursing education. The work of Rosenkoetter and Milstead, revising a previous version of Rosenkoetter’s code of ethics for nurse educators, is one of the very few examples. This has led us to propose a framework for ethical decision making in nursing education (see Figure 8-1). We based the framework on (a) our knowledge and experiences as nurse educators; (b) our knowledge and experiences regarding ethical decision making; (c) diverse literature sources related to nursing ethics and health care ethics; and (d) nursing and other education sources (for example, CNA, 2017; Fowler & Davies, 2013; Freire, 1968/2018; Hartrick & Doane, 2013, 2015; ICN, 2021; McDonald, 2013a, 2013b; Rodney, 2017; Storch, 2013a, 2013b). We hope that nurse educators and nurse leaders will find the framework in Figure 8-1 below useful in addressing ethical concerns in nursing education.
In what follows, we emphasize areas that are often invisible in the nursing education literature (Fowler & Davies, 2013). We focus on: (a) educator impairment; (b) teaching sensitive topics; (c) lack of response by a nursing leader in clinical practice to an educator’s concern; and (d) inequities of care based on the socio-political context.
Ethics in Practice Scenarios

In Ethics in Practice 8-1, professional impairment is understood as a professional’s inability, or lack of capacity, to engage effectively in practice. In our literature review, we discovered few studies where researchers explored impairment of nurse educators. Fowler and Davis (2013) found that educator and student impairment is invisible in the literature, although impairment in practice is well described. However, we located some studies related to impairment of nursing students (Dittman, 2015; Spier et al., 2000). While impairment in nursing is frequently associated with substance use (Contenta, 2019; Dittman, 2015; Dulaney, 2016; Spier et al., 2000), there are several other factors, such as work-related stress (Gustin et al., 2020), fatigue, and/or illness (Spier et al., 2000), that could also account for a professional’s inability, or lack of capacity, to engage effectively in practice. One should avoid making assumptions throughout the analytic process.

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ETICS IN PRACTICE 8-1

Educator Impairment: A Hard Conversation

You are an experienced educator and faculty member at a university school of nursing in Canada. You enjoy your work, your colleagues, and the undergraduate and graduate learners. You value teaching as a relational process and strive to be ethical in your everyday practice as a teacher, researcher, and administrator. For example, you engage with learners to co-create safe(r) spaces and you welcome learners’ diverse views within these spaces.

You are in your office when a learner drops by to ask if they could speak with you about an issue they are facing. You invite them to sit down, and they express concern about a faculty member who arrives late to class, seems to lack presence when they are there (“spaciness”), provides minimal guidance and feedback on assignments, and shuts down questions when they arise.

Previously, this faculty member engaged with learners and teaching in ways opposite to what the learner describes is happening now. The learner believes they are not able to approach the teacher directly and are worried about the teacher, as well as the learners in the class.
After fully listening to the learner and clarifying any ambiguities, please use *A Framework for Ethical Decision Making in Nursing Education* to decide what to do.

There are several unknowns in this scenario, and one should not make assumptions. Perhaps the first question to ask is whether you are the right person to receive the concern. If not, support the learner to connect with the appropriate leader, and make sure the learner has the support and resources they need. Ensure confidentiality is maintained throughout the process.

If you are the right person to receive the concern, take a relational inquiry approach to communication, and consider ethical concerns at intrapersonal, interpersonal, and contextual levels for all involved (Hartrick Doane & Varcoe, 2015). This means looking at what is going on within individuals, what is going on between individuals, and what is going on around individuals (Hartrick Doane & Varcoe, 2015). As mentioned above, impairment in nursing is most often linked to substance use, but it is important to consider other factors, such as work-related stress, fatigue, and/or illness (as referenced above this Ethics in Practice narrative), that could also account for your colleague’s change of behaviour.

Taking a relational approach to the situation will support a thoughtful and compassionate process. This will, for example, avoid the stigma and judgment that nurses with substance use issues can face from colleagues and others (Contenta, 2019). Rather than facing judgment, colleagues need advocacy, support, respect for their privacy, and kindness, similar to what would be offered if illnesses unrelated to substance use were at play (Dulaney, 2016).

Academic institutions and clinical agencies should have transparent and clearly articulated policies and procedures in place that provide direction for those who need to address educator impairment (Dittman, 2015; Spier et al., 2000). Such policies and procedures should be known to leaders, educators, and learners in advance of needing to use them. Substance use, and impairment more broadly, should be covered in curricula (Dittman, 2015) and educator meetings, not only as they relate to clients but also as they relate to nurses, educators, and learners. Alternate-to-discipline
(ATD) programs supporting nurses who are impaired are becoming common in nursing practice (Contenta, 2019; Dittman, 2015; Fauteux, 2022). We believe they should also be embraced in nursing education. There are many professional resources supporting impaired nurses who work in clinical practice, (e.g., British Columbia College of Nurses and Midwives [BCCNM], 2022a, 2022b; CNA, 2017, pp. 33–35), which could be modified for the nursing education context. Even though the triggers that lead to substance use may differ for nurse educators and other nurses, and similarly, consequences for patients and students are different, there is always a possibility that nurse educators and students are at risk of causing harm to patients when working/learning/teaching in the clinical area. Educators and leaders need to consider the question of readiness. As a professional group, are we willing to examine this issue in nursing education? If not, why not? What can we do about it?

Finally, educators and leaders should create and maintain a safe(r) space (Anderson & Riley, 2020; Carello & Butler, 2015; Deller, 2019; MHCC, 2019) to promote a positive moral climate and facilitate a sense of moral community. While leaders play a large role in the formation of safe(r) spaces, there are responsibilities for all concerned. These spaces may mitigate the underreporting of substance use and other issues among educators and learners, as well as provide the opportunity for non-disciplinary approaches to be used, and for non-disciplinary solutions to be found.

In Ethics in Practice 8-2, we provide a scenario where educators would need to be skilled at addressing sensitive topics, illustrating the importance of principle three from the STLHE framework (Murray et al., 1996).
The Ethics of Teaching Sensitive Topics

You are an experienced educator who provides professional development workshops for nursing staff at long-term care facilities. Today, for the first time, you are facilitating a one-hour dialogue about racism in nursing education. The session has been urgently mandated by the leadership team, leaving you with little preparation time. You know how important it is to work with the group, especially when addressing sensitive topics.

The session gets off to a good start, but after about 30 minutes you can feel tension in the room. Participants sound angry when they respond to questions posed by the educator in the large group, and the small groups do not appear to be well chosen. You are trying to understand what is happening when you notice one registered nurse (RN) looking tearful and heading for the door.

You excuse yourself to check in and they disclose that the session has been “awful” for them. Specifically, they feel triggered and do not want to work with colleagues who have just made racist remarks about Indigenous persons. The RN shares that they are feeling quite unsafe and would like to be excused. You agree and arrange to meet with them the following day.

FOR REFLECTION: ETHICS IN PRACTICE 8-2

Please use A Framework for Ethical Decision Making in Nursing Education to decide how to proceed.

There are varying forms of racism—individual/internalized, interpersonal, institutional, and structural (Bowen & Ward, 2021)—and one should not underestimate the prevalence of racism in nursing education. The academy has been embedded in colonialism, where knowledge, ways of knowing, and epistemology are narrowly conceptualized (Crosschild et al., 2021) and exclusive. To date, nursing has not prioritized confronting racism in nursing curricula (Blanchet Garneau et al., 2018). Consequently, there are calls to: (a) decolonize education curricula in nursing and other health professions (Blanchet Garneau et al., 2018; Canel-Çınarbaş & Yohani, 2019; CASN, 2020; Crosschild & Varcoe, 2021; Herzog et al., 2021; Pidgeon, 2016; TRC, 2015); (b) make curricula more inclusive in content, teaching, and learning processes (Canel-Çınarbaş & Yohani, 2019; CASN, 2020: Crosschild & Varcoe, 2021; Herzog et al.,
Leaders should ensure that educators are well supported when asked to take on sensitive topics. They should provide education and professional development for educators who are delivering anti-racist content (Acosta & Ackerman-Barger, 2017). Educators should have thoughtful and well-informed resources to guide this work (e.g., Canadian Association of Schools of Nursing [CASN], 2020; EQUIP Health Care, 2017). Preparation is key. Educators need to anticipate what they might encounter and prepare thoroughly and thoughtfully. Doing so requires cultural humility (Herzog et al., 2021), as well as moral courage, and a deep commitment to engaging in anti-racist education.

Educators and institutions are obliged to cover sensitive topics such as racism, and it is crucial to build safe(r) spaces to do so; but safe(r) spaces may not always be easy or relaxing spaces (Anderson & Riley, 2020; Heath et al., 2017). One way to alleviate potential harm when addressing sensitive topics is to use a trauma-informed approach (Heath et al., 2017). Carello and Butler (2015) describe this approach in education as trauma-informed educational practice (TIEP); its purpose is “to remove possible barriers to learning, not to remove traumatic, sensitive, or difficult material from the curriculum” (p. 265). For example, the physical environment, teachers’ ways of being, and/or students’ communication styles can all present barriers to learning (Carello & Butler, 2015).

Not surprisingly, educators may be reluctant to address racism and resistant to participate in teaching an anti-racist curriculum (Acosta & Ackerman-Barger, 2017). These topics can be intimidating, especially without support. However, educators have a responsibility to interrupt and disrupt racist discourses when they encounter them (Blanchet Garneau et al., 2018). Learners and educators should have resources in place (Anderson & Riley, 2020; Heath et al., 2017) for follow-up support. There needs to be institutional support to organize dialogue about racism and to be proactive in these initiatives. Crosschild and Varcoe (2021) call on nurse leaders to “tackle Indigenous-specific racism in healthcare and education through policy and education … with a collective
commitment to antiracism and decolonization at every level in education, research and practice” (p. 147).

In Ethics in Practice 8-3, we focus on a situation in which a senior RN is involved with a group of undergraduate students on a medical clinical unit. Two of the students approach their clinical instructor (CI) and report that they are experiencing bullying from the senior RN. The students do not believe that they can speak directly to the RN; they are in a “power-over” situation. The CI approaches the nursing leader on the unit, but reporting the concern does not appear to change anything.

### Ethics in Practice 8-3

**Sweeping a Complaint Under the Carpet**

You are the patient care coordinator (PCC) on a unit where there is a group of nursing students engaged in their 10-week clinical placement. You hope they will get their full-time hours, as there have been many student placement cancellations because of the global pandemic. You arrive one morning to a message from the students’ CI asking if they might speak with you. This is unusual so you hope everyone in the group is well.

Just before lunch, you have a chance to call the CI into your office, where they disclose that two students are being bullied by one of the RNs. You do not want this issue to escalate, so you reassure the CI that you will investigate the concern. However, you plan to have only a cursory talk with the RN (someone you are very confident in), because “rocking the boat” is not on your agenda today.

Two weeks later, nothing has changed, and the two students continue to feel belittled, humiliated, and afraid to ask questions. The RN's bullying has not only put the students' learning in jeopardy, but also risks lowering the quality of their patient care. The CI requests another meeting, so you know that you need to rethink and change your approach.

### For Reflection: Ethics in Practice 8-3

Please draw on *A Framework for Ethical Decision Making in Nursing Education* to plan for the meeting.

Researchers report that bullying is experienced by 50% of Australian students (Birks et al., 2017), 35% (Birks et al., 2017) and 42% (Tee et al., 2016) of students in the United Kingdom, 89% of Canadian students (Clarke et al., 2012); and more recently, 70% of students in
eastern Canada (MacDonald et al., 2022). Nurses and nurse educators have a long history of bullying (Daly et al., 2020), and some authors suggest that it is worsening (Birks et al., 2018). Even though zero-tolerance policies are recommended as potential solutions, they can give a false sense of reassurance that bullying is not happening. But the bullying may have gone underground (Borgwald & Theixos, 2013), or is being ignored (Hutchinson & Jackson, 2015).

There are guidelines in the anti-bullying literature that point to effective strategies. For example, cognitive rehearsal—a strategy that gives learners an opportunity to practice pre-designed scripts aimed at responding to bullying—is a helpful educational activity that has been successful in tackling bullying (Fehr & Seibel, 2016; Griffin, 2004; Griffin & Clarke, 2014). However, cognitive rehearsal is a strategy aimed at bullying at intrapersonal or interpersonal levels; bullying is a multi-faceted phenomenon, steeped in power structures and dynamics, and made more complex by the covert nature of many bullying practices (Hodgins et al., 2020; Hutchinson & Jackson, 2015).

It is crucial to also acknowledge the “need for organizations to move beyond the current individualistic understanding of bullying towards a more nuanced understanding of how anti-bullying policies and procedures are themselves an exercise in institutional power protecting and reinforcing dominant power structures” (Hodgins et al., 2020, p. 265). Bullying can become a legitimized form of power enactment, discouraging internal reporting and negatively affecting the “ethics and safety culture” within an institution (Hutchinson & Jackson, 2015, p. 20). For example, bullying that is ignored, silenced, or used when providing performance reviews can position the bullying as legitimate behaviour within the culture of the group. Hodgins et al. (2020) maintain that policies to address bullying are often designed to protect the organization rather than the person being bullied, and this may be why it is not uncommon for leaders to respond by doing nothing. When this occurs, it is important to acknowledge that the issue may be as a result of anti-bullying policies at the level of the institution, rather than what is included in more general nursing resources, such as national and international codes of nursing ethics, and guidelines of professional associations. (BCCNM, 2022b; CNA, 2017, pp. 33–35).
Such resources can be useful for nurses in responding to bullying in general, especially when leaders respond by doing nothing about the bullying that is occurring.

O’Flynn-Magee et al. (2021) argue for the importance of doing something to effect change, rather than doing nothing. Naming a behaviour as bullying, and acknowledging its ethical context, can have a powerful effect on recognition and acknowledgement of the issue by individuals and institutions. However, naming bullying may also uncover resistance to addressing it at individual and institutional levels. Institutions need transparent and easily accessible policies and procedures explicitly naming bullying as unacceptable; reviewing an institution’s core values should be the first step in the process (Hodgins et al., 2020). This requires institutional and leadership support to initiate and maintain anti-bullying policies, procedures, and processes. Similar to the previous situation about racism, educators may be reluctant to address bullying and participate in teaching an anti-bullying curriculum. As with racism, educators have a responsibility to disrupt bullying interactions when encountering them. Institutions should have both proactive and responsive supports and resources in place (Anderson & Riley, 2020; Heath et al., 2017; O’Flynn-Magee et al., 2020) that aid in the prevention and management of bullying. Institutions should also provide follow-up for learners, educators, and leaders such as the PCC in the scenario above. Educators and leaders have a unique opportunity to shape the future of nursing practice cultures so that bullying is no longer accepted as a practice norm. When nurse leaders receive complaints, they need to listen and do something (Crosschild & Varcoe, 2021), thus nurturing positive moral climates in nursing education and practice.

In our own work to address bullying in nursing education, prioritizing learner/educator partnerships from the outset has strengthened the credibility and thoroughness of our work. Our partnerships have fostered mutual learning between learners and educators, as well as strengthening collegial relationships, and sharing an ongoing commitment to our work together (Poon et al., 2022). We have learned that partnerships can benefit not only learners and educators, but also education institutions (Cook-Sather et al., 2014).
In Ethics in Practice 8-4, we describe a complex ethical situation at the socio-political level. At times, learners may be unaware of the complex contexts in which decisions, protocols, and policies are enacted. One example of that complexity is ensuring that Canadians have appropriate access to health care in the case of medical assistance in dying (MAiD). We use this situation as an illustrator for the ethical considerations that nurse educators and learners need to address.

**FOR REFLECTION: ETHICS IN PRACTICE 8-4**

Difficult Accessing Health Care

You are the supervising educator for a group of RN learners who are completing their advanced practica in two locations: a rural community setting and a rural hospital setting. They are learning a great deal and are well supported by the RN staff. The hospital to which they are assigned is faith-based, and individuals who request MAiD can neither be assessed for, nor receive, MAiD in this institution. While these policies are mandated in this facility, some faith-based health care institutions do offer MAiD (Sarick, 2020).

The RN group has debated the issue of access to MAiD in class, thus promoting critical pedagogy and education for social change. One of the RN learners is caring for someone who is about to request MAiD in the small rural hospital where they are currently hospitalized. The RN learner comes to you, as their educator, to help advocate for their client’s request to have MAiD in a place where the client is known and feels secure.

Please use *A Framework for Ethical Decision Making in Nursing Education* to decide how you will respond.

In Canada, MAiD became law in 2016, giving adult Canadians the legal right to access MAiD as a health care entitlement if they meet the eligibility criteria articulated in federal legislation (Pesut et al., 2020; Schiller et al., 2019). Nurses grapple with the diverse moral challenges embedded in decisions to participate or not in MAiD (Pesut et al., 2020). Nurse leaders in the area of MAiD are instrumental in making sure that patients can access the care they need (Thiele & Dunsford, 2019), and they also provide nurses with
morally safe spaces to learn through dialogue about any aspect of MAiD (Beuthin & Bruce, 2018; Thiele & Dunsford, 2019).

In education, when complex concerns arise regarding issues such as MAiD, it is crucial to prioritize time with learners to engage in discussion and invite them to share their perspectives. There are varying views about MAiD as a health care option (Kirby, 2021; Suva et al., 2019), and diverse perspectives about ensuring easy access to MAiD across faith-based and secular health care facilities (Kirby, 2021; Shadd & Shadd, 2019; Sumner, 2019). As RNs, some of the group in Ethics in Practice 8-4 may already have professional or personal experience with MAiD. Using a trauma-informed approach (Carello & Butler, 2015; Heath et al., 2017) can contribute positively to safety in an educational space such as this one.

Educators should engage in critical conversations with RN learners about accessibility to MAiD. The problem of inequitable access to MAiD across faith-based and secular health care institutions continues to be a fractious issue in Canada (Kirby, 2021). Thus, it is essential not to make assumptions that every faith-based institution is unable to support MAiD.

Supporters of institutional conscientious objection (ICO) claim that the right to conscientious objection (CO) for individuals should also be available to institutions (Kirby, 2021). While ICO is assumed to be based on religious grounds, other reasons, such as self-governance, or lack of professional expertise, are sometimes ignored (Shadd & Shadd, 2019). Opponents argue that ICO interferes with an individual’s right to access health care, as well as a health care professional’s moral and legal right to provide MAiD (Kirby, 2021). Kirby concluded that “nonconditional accommodation on the basis of ICO to MAiD is ethically unacceptable in Canadian health care jurisdictions” (p. 1). Kirby proposed a modified version of ICO with several eligibility criteria, one of which is the location of MAiD. In the case of MAiD in institutions, Kirby indicated that MAiD would need to be attached to the primary facility so that there would be minimal disruption and harm when a patient required transfer.

Nurses are well positioned to advocate for clearer MAiD policy (Beuthin & Bruce, 2018; Schiller et al., 2019), which will benefit patients, their families, communities, and nurses. While nursing education is an ideal place to foster learners’ political activism
(Banner et al., 2019; Buck-McFadyen & MacDonnell, 2017), it requires leadership buy-in and active support at academic, regulatory (Buck-McFadyen & MacDonnell, 2017), and practice levels. Educators and leaders can support learners’ critical understanding of MAiD, as well as other ethically challenging scenarios. For example, learners could discuss the importance of equitable access to chronic illness care and palliative care so that MAiD does not become a default decision at end of life. RN learners should understand the controversies, policies, and legislation that underpin access to care in their practice location. In what follows, we articulate our overall recommendations for nurse educators and leaders regarding ethical practice in nursing education.

**Top “Ten Plus One” Tips for Nurse Educators and Leaders**

1. Be clear and confident about the theoretical approaches and ethical guidelines that inform your teaching practice.

2. Consider how power and hierarchies play out in nursing education. What is your role and the role of others to mitigate the potentially negative effects of power and hierarchies?

3. Broaden the conceptualization of advocacy beyond the individual patient to include healthcare resourcing and provision, and see systemic change as important as change at the bedside (Scott & Scott, 2021, abstract).

4. Ensure that ethical concerns across levels in education (beyond education about ethical content) are visible and addressed in your practice area.

5. Honour relationships as the core of teaching and learning processes.

6. Support learners to develop and enact their moral agency.

7. Foster the capacity of educators and leaders to practice, teach, and advocate for their ethical obligations.
8. Advocate for educators to be acknowledged and valued as advanced practice nurse leaders in relation to ethical practice.

9. Support each other to be ethical learners, ethical teachers, and ethical leaders.

10. Encourage yourself, learners, and other educators and/or leaders to be politically minded and to acknowledge the responsibility to articulate ethical concerns and advocate for change.

11. Promote and foster scholarship that advances knowledge and ethical practice in nursing education.

**Conclusion**

Nurse educators, leaders, and learners should be inspired and directed by ethical, theoretical, and philosophical underpinnings that are consistent with their own beliefs and values and are congruent with the values and standards of their profession. We have described theoretical and philosophical perspectives to help guide educators in their ethical teaching in nursing education. Based on our analyses of educational processes, our experiences as educators, and our own beliefs and values about nursing education, we support critical pedagogy, anti-racist curricula, and Indigenization of nursing education, as reflected in the theoretical sources we have cited in this chapter. While these sources provide us with our “go-to” guidelines, we acknowledge there are many others. We therefore invite educators, leaders, and learners to reflect on the theories and philosophies that guide their ethical practice.

The role of space (physical, psychological, and spiritual) in nursing education is illustrated in the scenarios we presented in this chapter. Safe(r) spaces can be co-created through critical dialogue by those involved in the teaching and learning processes. Trusting relationships between learners and educators are at the core of safe(r) spaces in higher education (Anderson & Riley, 2020). Educators can use trauma-informed education practices (Anderson & Riley, 2020; Carello & Butler, 2015) to enhance those spaces.
The importance of the role of nurse leaders cannot be overemphasized. Cook-Sather and Felten (2018) encourage academic [and clinical practice] leaders to move from a neoliberal dogma to a pedagogy where partnership, reciprocity, and inclusivity are welcomed and encouraged. Such practices require leaders, educators, and learners to share foundational beliefs and values.

While ethical concerns in nursing education may present themselves at the intrapersonal or interpersonal levels, there are usually complex systemic influences that may or may not be visible. Hartrick Doane and Varcoe (2013) emphasized that “people are contextual beings who exist in relation with others, and with social, cultural, political, and historical processes” (p. 150).

Nurse educators and leaders face challenging contexts, including global pandemics, neoliberal mandates in health care, corporatization of higher education, and nursing shortages. Despite these factors, educators can make choices. While some things are beyond our capacity to change—for example, our past experiences—it is never too soon or too late to be an educator, leader, or learner who engages in dialogue and commits to relational practice. This entails acknowledging the importance of socio-political contexts; striving to engage in practice with critical curiosity, humility, and respect; and supporting transformative learning and ethical action in nursing education.

QUESTIONS FOR REFLECTION

1. What are your thoughts about Fowler and Davis’s (2013) view that “the entire domain of ethics in nursing education is, itself, taboo” (p. 129)?

2. Throughout the chapter, we have emphasized the importance of context for ethical practice in nursing education. How does context influence your practice as an educator, leader, or learner?

3. There is no shortage of ethical concerns in nursing education. Can you identify one issue that requires immediate action? For what reasons would you prioritize this issue rather than one of the many others that pervade nursing education? What role would you be willing to take? How would you decide what is needed, and what to do?
4. *We have described several theoretical underpinnings that guide practice for nurse educators. What influences your practice each day? Consider this question using a theoretical, ethical, and relational lens.*
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APPENDIX 8-1

Individual Reflective Exercise

**IT IS IMPORTANT TO REFLECT ON VALUES** about teaching, learning, leadership, and context, and to make connections between values and the theoretical frameworks that guide practice. One tool that readers might find helpful is Pratt and Collins’s (2000a, 2000b) Teaching Perspectives Inventory (TPI). Reflecting on the TPI enables a focus on teachers’ beliefs, intentions, and actions, and can be an insightful way for educators to learn about themselves as teachers. Below is a reflective exercise that you can use to consider the varying components of your practice.

At times, you may find it challenging to name the theoretical underpinnings of your practice. It may be helpful to consider Hartrick Doane and Varcoe’s (2015) view that practice is never atheoretical. And even though you may not be conscious of the foundational underpinnings of how you engage in teaching, taking time to think about it will serve you well.

Please take a moment to (1) complete the TPI (http://www.teachingperspectives.com/tpi/) and (2) reflect on the values, theories, concepts, and frameworks (pedagogical, ethical, relational) that guide your everyday teaching practice. Once you have identified and analyzed them, note them in your educator
toolbox (refer to Figure 8-1-1). Be as creative as you would like to be—write, draw, paint, doodle.

**FIGURE 8-1-1**

*An Educator Toolbox*

![Diagram of an Educator Toolbox](image)

**REFLECTIVE QUESTIONS**

Now that you have completed your reflections and TPi, ask yourself the following questions:

1. *What was the experience like for me?*

2. *What surprised me about either exercise?*

3. *How has the exercise affected my thinking about teaching and learning?*

4. *What does it mean for me as a nursing educator and/or leader now and in the future?*
THE UNITED NATIONS, in its 2030 Agenda for Sustainable Development (2015), points to important goals for health systems globally, including “[t]o ensure healthy lives and promote well-being for all at all ages,” and “[r]educed inequalities” (p. 3). However, we have yet to achieve these goals, or the other 15 listed; meanwhile, there are new threats and widening gaps in health and wealth which continue to emerge. The global pandemic of COVID-19, declared by the World Health Organization (WHO) in March 2020, exposed and deepened pre-existing inequities in health and impacted the ability of many to
stay at home safely. Alongside an infectious disease pandemic, “pandemics” of racism, domestic violence, drug overdose deaths, poverty, and homelessness—escalated by systemic restrictions to prevent the spread of COVID-19—were further exposed. More than a decade ago, the WHO (2008) emphasized the importance of closing the gap in health in the next generation by addressing the conditions in which we live and work. These conditions are known as the social determinants of health (SDOH).

Nurses have played an unprecedented and critical role in ensuring the health and safety of individuals, families, and communities through activities aimed at preventing COVID-19 and providing care for those with COVID-19. In every aspect of the pandemic response, nurses have been front and centre. Nurses have rapidly responded to individual, community, and population-level health needs, which is characteristic of their deep ethical commitments to care for others. For example, public health nurses stepped up to provide education, testing, and contact tracing, and to facilitate rapid uptake of vaccines. In hospitals and communities, nurses have cared for those who are sick, as well as those who are highly vulnerable and susceptible to COVID-19. This response has come at a high cost to nurses themselves. Nurses have raised alarm bells about the cracks in our systems, voicing concerns about the health and well-being of the nursing workforce. During COVID-19, the visibility of nursing work and the stresses associated with that work have never been greater (Abuatiq, 2021).

Nurses often witness people experiencing systemic inequities in the health care system, and therefore are able to highlight and bring awareness to these inequities (Pauly et al., 2021; Scott et al., 2020). This duty to advocacy bears its own cost to health care providers (HCPs). Working in the context of deep inequities and systemic violence—such as often-undeclared and ongoing emergencies related to structural racism, violence, drug overdoses, homelessness, and poverty—are less visible sources of overwhelming workloads and distress for nurses, particularly in community and public health nursing (Marcellus et al., 2022). As such, there is a tension between advocating for the profession at the same time that there is an urgent need to advocate for reducing inequities and promoting health equity. This is both a challenge and an opportunity, requiring
a depth of knowledge and understanding that is often not available within health systems (Farrer et al., 2015; Wright et al., 2022).

Health equity is a fundamentally ethical concept. Canadian health systems have goals related to achieving health equity, and nurses have a professional and ethical commitment to the promotion of health equity (Baum et al., 2009; Canadian Nurses Association, 2017). However, within these systems, there are ethical issues associated with promoting health equity that have been termed the “health equity curse” (Pauly et al., 2021). Health systems are dominated by ideological commitments that privilege individualism, biomedicine, and capitalism, and are steeped in settler colonialism and racism—all factors which can negatively impact health equity (Allan & Smylie, 2015; McGibbon et al., 2021). It is difficult to promote health equity, as within conflicting value systems, equity and equality may not be prioritized. Furthermore, while health equity may be upheld as a value in theory, there is little critical understanding of the concept in practice, or of the actions its achievement would require (Marcellus et al., 2022; Van Roode et al., 2020).

In this chapter, we name ethical issues associated with health inequities, and we locate these inequities within a critical social justice perspective that highlights power imbalances and the structural and systemic conditions that create inequities (Farmer, 2001, 2009; McGibbon & Lukeman, 2019; Navarro, 2009; Stevens & Hall, 1992; Young, 1990). We examine strategies for navigating these issues in practice, therefore promoting a vision of health equity that is more in line with the stated goals of health systems. First, we provide some definitions of basic concepts central to understanding professional goals and commitments related to health equity. Understanding of core concepts, such as health equity and inequities, the social determinants of health, and social justice, are central to advanced nursing practice. This knowledge helps nurses to name issues and thus informs their understanding and action on professional ethical commitments.
Social Determinants of Health, Health Equity, and Critical Social Justice

Social Determinants of Health

An array of social factors, beyond health systems and services, influence individual health and the overall health of the population (Mikkomen & Raphael, 2010; Navarro, 2009). We often refer to these social conditions as the social determinants of health. Simply stated, where we are born, live, work, and age matters to our health (WHO, 2008). As noted by the WHO’s Commission on the Social Determinants of Health,

The poor health of the poor, the social gradient in health within countries, and the marked health inequities between countries are caused by the unequal distribution of power, income, goods, and services, globally and nationally, the consequent unfairness in the immediate, visible circumstances of peoples’ lives—their access to health care, schools, and education, their conditions of work and leisure, their homes, communities, towns, or cities—and their chances of leading a flourishing life. This unequal distribution of health-damaging experiences is not in any sense a “natural” phenomenon but is the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics. Together, the structural determinants and conditions of daily life constitute the social determinants of health and are responsible for a major part of health inequities between and within countries. (Commission on the Social Determinants of Health, 2008)

The social determinants include both material and non-material factors that influence health (Graham, 2004). Material determinants include housing, income, education, and other resources, while non-material determinants refer to elements that impact advantage and disadvantage, such as privilege, race, sex, gender, and social class. These elements are the
interrelated social, political and economic factors that create the conditions in which people live, learn, work and play. The intersection of the social determinants of health causes these conditions to shift and change over time and across the life span, impacting the health of individuals, groups and communities in different ways. (National Collaborating Centre for Determinants of Health, n.d., emphasis in original).

Importantly, social positioning matters to health with the recognition that individuals, groups, and communities are differently positioned within existing social conditions and such conditions are embodied in relation to health, illness, and disease (Friel et al., 2011; Kreiger, 2009). One way of understanding this is to use an intersectional lens to consider differing dimensions of sex, gender, class, ethnicity, and ability (Crenshaw, 2005; Dhamoon & Hankivsky, 2011).

Intersectionality refers to social positioning and how individuals are positioned in relation to overlapping systems of oppression and advantage (Cole, 2009; Varcoe et al., 2012; Walby et al., 2012). The particular set of conditions and positioning affecting each individual’s health care is not simply additive; it is multiplicative, creating advantage and disadvantage within systems that simultaneously privilege and discriminate (McCall, 2005). In Canada, this can be seen in the benefits White settlers have enjoyed from colonization and capitalism, while Indigenous people were stripped of land and resources and suffer ongoing generational impacts of systemic racism (Reading & Wien, 2009).

**Health Equity**

Health inequities are produced and reproduced by structural injustices deeply rooted in policy and political processes. For example, it was a political decision to disinvest in social housing in the 1990s and treat housing as a commodity rather than as a basic social good or a determinant of health (known as the financialization of housing; Office of the High Commissioner for Human Rights, n.d.). Health inequities are systemic injustices that are unfair, potentially
modifiable, and remediable (Crombie et al., 2005; Whitehead & Dahlgren, 2006). Conversely, health equity means everyone (individuals, groups and communities) has “a fair chance to reach their full health potential and are not disadvantaged by social, economic and environmental conditions” (National Collaborating Centre for Determinants of Health, n.d.). While health equity is a goal of health care systems (Baum et al., 2009), health systems are permeated by biomedical values, as well as the ideologies of capitalism, neoliberalism, and colonialism that contribute to systemic inequities (Allan & Smylie, 2015; McGibbon et al., 2021; Pauly et al., 2021). As such, health systems are falling short of meeting espoused goals of health equity. Thus, although health equity may be a stated value in health systems, it may not be prioritized over other competing priorities and ideologies (Van Roode et al., 2020). Further, health equity is often not well understood, and nurses, policymakers, and others have very different understandings of what health equity means (Pauly et al., 2017).

Equity is often confused with equality. Health inequalities refer to differences in health outcomes between groups in the population without any moral assessment of fairness or justice. When these differences are produced by systemic and structural conditions and are potentially remediable, these differences are known as inequities (Whitehead & Dahlgren, 2006). For example, people who are unhoused often have poorer health and die prematurely compared to the rest of the population because they lack a fundamental material determinant of health: a place to live (Hwang et al., 2009). This issue is systemic because housing has become a commodity rather than a social good, resulting in a loss of social housing and a lack of investment in affordable housing. Structural violence, a term coined in the 1960s by Galtung, has been taken up in health and health care by social scientists to describe these sorts of social structures, institutions, and processes that prevent people from accessing basic resources for health, thus causing harm (Farmer, 2001, 2009; Rhodes et al., 2012).

So far, we have focused on health equities, as well as structural and systemic conditions that impact health. Yet most of the determinants of health fall outside of the health system, despite their major influence on health, meaning HCPs often lack a direct means
of improving outcomes for their patients. Gaps in health equity are compounded by inequities in access to health services. This is sometimes called the inverse care law, in that people who have the least access to resources for health also face the most barriers in accessing health services (Hart, 1971). Frequently, equity of access is a primary focus in health systems (Pauly et al., 2017). In part, this focus stems from the nature of acute care services, where there are concerns about various dimensions impacting access, such as geography, gender, ethnicity, and ability. Health systems are typically not oriented to public health and the SDOH, as the focus of health systems is biomedical and acute care.

**Critical Social Justice**

While traditional approaches to bioethics have centred on distributive justice, the achievement of health equity centres on social justice. Beauchamp (1976) highlighted the connection between social justice and acting on the determinants of health. Specifically, he wrote, “Public health should be a way of doing justice” (Beauchamp, p. 8). Peter (2004), drawing on Rawls, argued that social inequalities (differences in health) are wrong when they stem from unjust social, political, and economic institutions, thus embedding “the pursuit of health equity in the pursuit of social justice in general” (p. 160). Iris Marion Young (1990), when discussing feminist and relational bioethics, highlighted that conditions shaping distribution of resources, including power and privilege, are critical to social justice. In order to achieve fairness, participation of those impacted by inequities is central to the achievement of health equity. Fraser (2007) identified the importance of social arrangements that allow for participatory parity, with parties being able to participate as equals based on a three-dimensional theory of justice: recognition, redistribution, and representation. As will be discussed later, engaging with the individuals impacted by health inequities is a cornerstone of equity-oriented action. These individuals often have less power, advantage, and resources in society, and are often underrepresented in health and social systems.
McGibbon and Lukeman (2019) outlined the core features of a critical perspective for informing critical social justice for nursing. These included

1) explicit analyses and critique of hegemonic power structures and ruling relations; 2) organized public protest and acts of resistance in the face of oppressive, often murderous, regimes, public policies, and the like; and 3) explicit goals of disrupting, unsettling, and interrupting processes and practices of oppression in local and global spheres (all of which are synergistically connected). (p. 4)

Thus, reducing health inequities requires fundamental shifts and redistribution of power. Unfair and inequitable structures and processes must be changed to enable a better distribution of wealth, resources, and privilege in society. The complexity of changing structures and processes makes it challenging to shift organizations and systems towards equity. In what follows, we present an Ethics in Practice scenario where we highlight challenges in regard to changing structures and processes, particularly when racism is involved. As we describe below, racism can be both a determinant of health and a cause of inequitable access to health care.

**ETHICS IN PRACTICE 9-1**

**Racism in Health Care**

On September 28, 2020, Joyce Echaquan, an Indigenous woman, died in a Montreal hospital after being subjected to abusive remarks from nursing staff. The words and actions were captured on video and shared on social media (Page, 2021a). While the investigation into her death found that understaffing played a role, the comments and actions of the nurses were inconsistent with professional codes of ethics and practice standards (Page, 2021b.) Furthermore, this was not an isolated incident, as there have been many reports of racism in health care experienced by Indigenous people. For example, in June 2020, there were media reports of allegations that staff in a BC emergency centre played a game to guess blood alcohol levels of Indigenous patients. A systematic inquiry into this situation (British Columbia Ministry of Health, 2020) found that 84% of Indigenous people have experienced racism in health care. For example,
Indigenous people who did not drink alcohol were told not to drink; in other situations, they were assumed to be intoxicated when they were not.

As illustrated in the Ethics in Practice scenario above, racism is a determinant of health and acts as a deterrent that limits access to health care (Reading, 2015). For Indigenous people in Canada, racism is deeply rooted in health and social systems. In a 2015 study, First Peoples, Second Class Treatment, Allan and Smylie described how racism against Indigenous people in the health care system was a major factor contributing to poor health among Indigenous people across Canada. The researchers found that Indigenous people experienced so much racism from health care workers that they often strategized ahead of time about how to deal with racist behaviour before visiting emergency departments, or they avoided hospitals altogether.

Racism, whether conscious or unconscious, impacts the care nurses provide. Nurses are in a position to call out racism. However, nurses often remain silent and, further, do not always recognize the historical role they have played in the marginalization of racialized people in Canada. For example, until their discontinuation in the early 1980s, “Indian hospitals” racially segregated Indigenous people from others, often displacing them from their communities with requirements to travel thousands of kilometers to the nearest facility, and providing harsh and inhumane treatment. Thus, Indigenous people have a legacy of well-earned distrust in the Canadian health care system (Lux, 2016). In fact, the Indian Act of 1985 (Government of Canada, 1985) can compel hospitalization for Indigenous people to this day.

As a way to provide more direction to nurses regarding racism, national and professional nursing organizations created a nursing declaration on anti-Indigenous racism (Canadian Association of Schools of Nursing & Canadian Indigenous Nurses Association, 2021) that affirmed the importance of the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2007) and reports of the Truth and Reconciliation Commission’s Calls to Action (Government of Canada, 2015). Given that there is a pressing need to address Indigenous racism in nursing, we believe that advanced practice nurses have the expertise and are in key leadership roles to facilitate change in education, policies, and culture.

* Refer to Chapter 20 for another discussion of this case.

**Naming Ethical Issues in Promotion of Health Equity**

Ethical issues related to the promotion of health equity frequently go unrecognized and unnamed in nursing practice. In what follows, we describe a number of equity issues that emerge in multiple settings, including in hospitals, public health clinics, and primary care.
settings, as well as community and outreach services. These issues surfaced in research with public health providers who focused on ethical issues that arose in the context of promoting health equity (Pauly et al., 2021). They highlighted tensions that occurred as nurses and other practitioners tried to navigate different agendas in systems where health equity was not necessarily prioritized. We briefly describe some of the issues in the next section.

**Conflicting Values**

Health systems dominated by values that are integral to biomedicine include an emphasis on managing illness and disease within a system focused on acute care. Public health, in contrast, has explicit commitments to health equity and promotion of the determinants of health, and is therefore more oriented towards preventative action than acute care. As a result, public health is often marginalized and underfunded. HCPs also do not necessarily have control of resources that impact all the determinants of health; for example, housing, income, and education, adding further barriers for public health practitioners.

**Individualistic and Biomedical Lenses**

Within acute care and biomedical systems, health inequities are blamed on the failures of individuals, who are also blamed for any negative situations in their lives which contribute to poor health. There is often little attention paid to broader structural or systemic conditions that impact both the health of individuals and the health of communities as well as subgroups in the population. This is ethically concerning because of a failure to recognize harms and vulnerabilities that are a product of structural violence and systemic conditions. Individuals, groups, and communities should be self-determining; however, when caregivers individualize or medicalize a person’s situation or concerns, this contributes to harm and creates barriers to care.
Efficiency and Business Models (Capitalism) Versus Person-Centred Care

Public health providers have described an emphasis on bureaucracy and efficiency that often undermines and diminishes the ability of nurses to provide patient-centred care. This is critically apparent in the checklists and tick boxes that dominate care provision, as well as eligibility requirements for services (Pauly et al., 2021). Nurses are often unable to individualize or personalize care in the context of bureaucratic requirements, and frequently have to find workarounds or bend the rules in order to ensure that individuals receive the care they need. Additionally, in the context of stigma and discrimination, there is often a lack of respect, as well as more attention placed on surveillance and control rather than on trust and autonomy.

The issues described above are some of the ethical difficulties that nurses confront in daily practice as they care for vulnerable patients facing threats to their health. It is a sampling rather than an exhaustive list. To further illustrate some of these issues, we provide the following Ethics in Practice scenario where we describe the need for structural and systemic attention to health inequities.

**ETHICS IN PRACTICE 9-2**

*Structural, Systemic, and Individual Determinants of Homelessness*

Homelessness is a product of systemic and structural issues that intersect with personal situations, such as job loss or injury (Gaetz et al., 2016). The root causes of homelessness in Canada include poverty, loss of social housing, neoliberalism, capitalism, and colonialism. Indigenous people are over-represented among unhoused populations due to displacement and loss of lands and resources. Homelessness is often medicalized, problematized, and stigmatized as an individual problem, a mental health issue, a substance use issue, or some combination of the three. Prior to and during COVID-19, encampments became increasingly visible across Canada, and communities grappled with how to respond to visible homelessness. For many, the privilege of staying at home was not possible. People living outdoors and in encampments do not have access to the basic requirements for health, such as housing, income, public sanitation, garbage disposal, food, privacy, and safety. These
Multiple Forms of Stigma and Discrimination

As illustrated in the Ethics in Practice examples presented so far, stigma and discrimination are fundamentally ethical issues that violate basic principles of respect and dignity. These issues involve moral judgments about persons in terms of their worth and value as people, including a lack of recognition and respect for human rights and the ability to be self-determining. Stigma and discrimination have similar roots, but some authors distinguish between the two (Ahern et al., 2007). Stigma is often associated with marginalizing a person or group because of their particular behaviours; some conditions that are highly stigmatized include illicit drug use and mental health issues. Discrimination, on the other hand, is focused on the innate characteristics of individuals which “other” them, such as race, sex, and gender.

Enacting stigma is a form of power in which one group has the ability and authority to label, stereotype, and judge others on the basis of certain characteristics or behaviours (Link & Phelan, 2014).
Labels and stereotypes are based on assumptions and moral judgments about people and groups. Stigma is harmful and has a negative impact on the health and well-being of those who are stigmatized (Biancarelli et al., 2019; Couto e Cruz et al., 2018; Gee et al., 2012). Racism, sex, and gender discrimination, as well as discrimination on the basis of poverty and homelessness, impact health and act as barriers to health care services (Allan & Smylie, 2015; Chan Carusone et al., 2019; Gabet et al., 2019). Abusive, stigmatizing, or discriminatory comments are inconsistent with the professional and ethical commitments of nurses to treat people with respect and dignity. In many ways, these kinds of negative behaviors reproduce the structural trauma that is already endemic in health and social systems.

**Professional Commitments to Health Equity and Social Justice**

Nurses and other HCPs should provide safe, competent, and ethical care in accordance with professional values that include commitments to health equity and social justice. These commitments are outlined in professional standards of practice and codes of ethics (Canadian Nurses Association, 2017). Nurses and others often find themselves at the nexus of ongoing systemic injustices, inequitable health systems, and commitments to promote health equity in the face of inequities. In Part I of the CNA Code of Ethics for Registered Nurses (2017), seven key values that nurses must uphold are outlined, including promoting justice. Nurses are specifically directed as follows:

F1. Nurses do not discriminate on the basis of a person’s race, ethnicity, culture, political and spiritual beliefs, social or marital status, gender, gender identity, gender expression, sexual orientation, age, health status, place of origin, lifestyle, mental or physical ability, socio-economic status, or any other attribute.

F2. Nurses respect the special history and interests of Indigenous Peoples as articulated in the Truth and

F3. Nurses refrain from judging, labelling, stigmatizing and humiliating behaviours toward persons receiving care or toward other health-care providers, students and each other. (p. 15)

Nurses have ethical responsibilities to promote justice and not discriminate against individuals. In practical terms, it may include not discharging individuals from care facilities into unsafe situations where they do not have a suitable place to live, or face domestic violence. Further, promoting justice should and must capture the ethical responsibilities of not discriminating against groups or communities. To this end, the authors of the CNA Code of Ethics highlighted the importance of knowing the history of Indigenous people, but in our view, this measure does not go far enough in combatting stereotypes, judgments, and labelling of Indigenous people and other groups. Further, all Canadian provinces and territories have human rights legislation prohibiting discrimination of groups and communities.

Part II of the 2017 CNA Code of Ethics also includes specific aspects of social justice and the ethical endeavors of nurses to improve systems and societal structures for greater equity. However, this portion of the CNA Code of Ethics is considered to be aspirational, non-binding, and in some cases, the responsibility of collectives rather than individuals. Yet, for public health and community nurses, this is central to their practice as outlined above, in that health equity is foundational to public health.

**Strategies for Ethical Nursing Practice**

To promote health equity in nursing practice requires a set of competencies that nurses should acquire during their nursing education or through continuing education. There are multiple strategies for gaining the knowledge and skills required to promote health equity. Advanced practice nurse leaders can role model, practice, and promote these skills as part of their leadership roles. Such strategies
can help shift thinking and cultures within health care organizations. Further, it is also important to shift policies at micro, meso, and macro levels, as educational opportunities alone will not be enough.

**Thinking Differently**

Thinking differently means using a different lens for how one views individuals, groups, and communities in practice. Using a dominant societal lens results in people seeing inequities as a problem of individuals (a view which aligns with neoliberalism) or as a problem of biomedicine. In addition, heteronormativity, gender bias, and ableism colour our thinking in ways that impact how we provide care. Thus, we have to think differently about individuals, groups, and communities, and how they are positioned in society, as part of the provision of ethical nursing care. Another way of saying this is to use one’s ethical imagination. For example, ask the question, what would it be like if I had to walk all night because there was nowhere safe to sleep?

Another aspect of thinking differently can be understood in terms of recognizing different social locations by drawing on intersectionality and social ecology. An intersectional lens helps us focus on how people are positioned differently within society, and an ecological lens helps us recognize the different contexts which impact experiences of those affected by inequities. The Systems Health Equity Lens (SHEL) was developed to guide nurses and other health care leaders when reviewing systems and creating organizational health equity plans (Pauly et al., 2018). The SHEL can be used by nurses in practice and leadership positions in many settings to encourage shifts in thinking about health equity.

Medical educators—particularly in social medicine, where the focus is on the social factors that contribute to health and illness—have embraced the idea of practitioners attaining structural competencies to understand how social conditions impact health for individuals (Metzl & Hansen, 2014). Learning is centred on understanding individuals and their circumstances, which extends to a structural understanding of why someone might not be able to follow a plan of care if they are, for example, living in an abusive situation or have to prioritize survival needs such as finding food.
and shelter. Experiential learning has also been highlighted as a way to mitigate stigma through human interactions with individuals experiencing inequities (Livingston et al., 2012).

**Understanding History and Policies**

Knowledge and understanding of history and policies that have produced inequities is essential to ethical nursing practice. This knowledge contributes to thinking differently about people and situations. Knowledge is essential to disrupt stigma and discrimination and accurately contextualize and understand situations and behaviours. In the 2017 CNA *Code of Ethics*, there is specific reference to understanding the history and ongoing influence of colonization, which is a critical context for understanding Indigenous mistrust of health systems. There are many avenues for gaining this knowledge, such as through programs like San’ıyas Anti-Indigenous Racism Cultural Safety Training (Provincial Health Services Authority, n.d.).

In Ethics in Practice 9-3 below, we share insights offered by an examination of the history and policies that underlie the current high rate of overdose deaths in Canada. We also discuss how the system can be improved by framing substance use as a social and political issue, rather than an individual failing.

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**ETHICS IN PRACTICE 9-3**

*Overdose Crisis Within a History of Drug Policy, Racism, and Colonialism*

Prior to 1908, currently illegal drugs, such as cocaine and heroin, were available in over-the-counter medications such as cough syrups. These substances were used by all sectors of society (Boyd, 2017; Boyd et al., 2016). Key catalysts for the current drug policy of prohibition were the 1907 race riots in Vancouver and the influence of the temperance movement led by White settler and immigrant forces. Within this temperance movement, abstinence was promoted, and moral corruption was associated with the use of substances. This view was fuelled by the anti-Asian and anti-Indigenous racism that was part of colonialization. Mackenzie King, the prime minister
at the time, visited Vancouver, and upon return to Ottawa advocated for prohibition policies that were meant to control Chinese migrant workers and immigrants. In 1908, the Opium Act was passed (Canadian Drug Policy Coalition, n.d.), and although the Act has been amended several times, it is still in force today. This long-standing legislation of prohibition is contributing to a high rate of harms for people who use drugs. The harms include an epidemic of drug overdoses related to an increasingly toxic drug supply, as well as stigmatization of people who use drugs.

Almost 25,000 Canadians died of a drug overdose between 2016 and 2021, with a dramatic increase in the number of deaths during COVID-19 (Government of Canada, 2021). Indigenous people are disproportionately impacted by drug overdose deaths due to high levels of trauma associated with colonization (First Nations Health Authority, 2017).

Ongoing overdose deaths are dramatically affecting communities in which nurses work—communities which are experiencing constant loss and grief. Understanding the history of prohibition is key to developing important drug policy reforms that can be part of collective nursing advocacy and action. Additionally, knowledge of the history of prohibition should help nurses recognize how some communities are disproportionately impacted, and how stigma, racism, and discrimination are founded on and fuelled by current drug legislation. Speaking out against stigmatizing and discriminatory care of people who use drugs is essential to counter prohibitionist rhetoric, which creates the political inaction that results in people dying daily. Advanced practice nurse leaders can set the tone in health care in terms of creating new norms, cultural attitudes, and understanding of substance use, reframing it as a policy and political issue rather than a moral and individual one.

Developing Trust

In situations of inequities, there are often high levels of distrust of health and social systems due to colonial and capitalistic systems of oppression. Institutions such as residential schools and Indian hospitals, and the poor treatment of Indigenous people at these institutions, have contributed to high levels of distrust. For people who use drugs, stigmatizing experiences are cumulative and generate distrust. Homelessness is the product of the failure of multiple systems, and people are distrustful of systems as a consequence. In light of this, the ability to build trust is a profound skill that can promote health equity as, in part, it can facilitate access to health care (Pauly, 2014b). According to the 2017 CNA Code of Ethics, “Nurses build trustworthy relationships with persons receiving care
as the foundation of meaningful communication, recognizing that building these relationships involves a conscious effort. Such relationships are critical to understanding people’s needs and concerns” (p. 8, emphasis in original). Although the work of developing trust in situations of distrust is complex and time-consuming, it is essential to promoting health and health equity.

The pathway to trust begins with respect. In Part I of the 2017 CNA Code of Ethics, the value of honouring human dignity encompasses recognizing and respecting the intrinsic worth of each person, and suggests that nurses should relate to all persons receiving care with respect. Relevant and important responsibilities written in the CNA Code of Ethics include

1. Nurses, in their professional capacity, relate to all persons receiving care with respect.
2. Nurses support persons receiving care in maintaining their dignity and integrity.
3. In health-care decision-making, in treatment and in care, nurses work with persons receiving care to take into account their values, customs and spiritual beliefs, as well as their social and economic circumstances, without judgment or bias.
4. Nurses intervene, and report when necessary, when others fail to respect the dignity of a person they are caring for or a colleague (including students), recognizing that to be silent and passive is to condone the behaviour. They speak up, facilitate conversation and adjudicate disputes, as appropriate/required. (Canadian Nurses Association, 2017, p. 12)

Speaking up requires skill, strength, and courage. Due to power imbalances among providers, this is not always easy or safe to do. It can be unpopular for nurses to advocate for some groups, such as people who are unhoused, and by doing so, nurses risk being marginalized by others (Pauly et al., 2021). Social movements are central to change, yet it can be difficult for nurses to engage in social movements, radical civil disobedience, and action because of legal implications for their careers and their abilities to remain registered.
as nurses in their jurisdictions. In what follows, we discuss advocacy and introduce the idea of allyship.

**Shifting Culture, Policies, and Practices**

**Advocacy**

Advocacy has long been important to ethical nursing practice (Curtin & Flagerty, 1982). A key area of advocacy is promoting recognition of systemic causes of inequities. Recognition of structural and systemic factors such as colonialism, neoliberalism, and capitalism, and how they operate in nursing, are important to attend to within our profession. This recognition is critical to the processes of accountability and social change.

Nurses are positioned uniquely within health systems and the community to act as advocates. They are highly respected and credible professionals who are closely connected to those for whom they provide care. Advocacy is not speaking on behalf of others, but advocating for and making space for the voices of those impacted by health inequities to speak for themselves (Canadian HIV/AIDS Legal Network, 2005). In nursing practice, this can mean accompanying and supporting a client to speak for themselves when they are attempting to access needed services. In program and policy development and implementation, this can include advocating that people impacted by inequities be directly included in processes of decision making and action. Forming true and equal partnerships with people experiencing inequities is central to the promotion of health equity (Marmot et al., 2008; Solar & Irwin, 2010). Advocating for involvement of people impacted by health inequities is a form of advocacy that is consistent with concepts of critical social justice as described by Young (1990) and Fraser (2007).

**Cultural Safety**

Cultural safety is a key component of ethical nursing practice. The term “cultural safety” was developed by nurses in New Zealand to address the barriers to care for Maori people (Nursing Council of New Zealand, 2005; Ramsden, 2000). A key principle is that safety is defined by those receiving care. Nurses must reflect on and inter-
rogate their own positions of privilege and power in relation to clients. This aligns with the 2017 CNA *Code of Ethics* responsibility under informed decision making that states: “Nurses are sensitive to the inherent power differentials between care providers and persons receiving care. They do not misuse that power to influence decision-making” (p. 11). However, being sensitive to inherent power differentials goes beyond just decision making; it should apply to all aspects of interactions between nurses and patients.

**Harm Reduction**

Reducing the harms of risky activities, such as wearing seatbelts when driving or using car seats, is part of preventing injury and illness. Another example would be the use of condoms to prevent transmission of sexually transmitted diseases. Applied to the use of substances (legal and illegal), the use of the term “harm reduction” refers to reducing harm, not to reducing use of illicit substances. Harm Reduction International (HRI; n.d.) provides this definition of harm reduction:

> Harm reduction refers to policies, programmes and practices that aim to minimise negative health, social and legal impacts associated with drug use, drug policies and drug laws.

> Harm reduction is grounded in justice and human rights. It focuses on positive change and on working with people without judgment, coercion, discrimination, or requiring that they stop using drugs as a precondition of support. Harm reduction benefits people who use drugs, their families and the community. (paras. 1 and 2)

HRI outlines the following commitments that are integral to harm reduction: (a) respecting the rights of people who use drugs; (b) commitment to evidence; (c) commitment to social justice and collaborating with networks of people who use drugs; and (d) avoidance of stigma. The goals of harm reduction are to keep people alive and encourage positive change, to reduce the harms caused by
drug laws and policies, and to offer evidence-based alternatives to abstinence from drug use (Harm Reduction International, n.d.).

Often, harm reduction is understood as a set of evidence-based interventions such as needle exchange, safer consumption (for example, Vancouver’s supervised site, Insite\(^2\)), naloxone distribution, and other interventions like managed alcohol programs that reduce harms of use without preventing use. Nurses have long been advocates for harm reduction. For example, they spoke in support of Insite, and drew on a significant body of evidence when they acted as intervenors during the federal Supreme Court hearing about Insite (Canadian Nurses Association, 2011). The critical role nurses played alongside other intervenors resulted in Insite remaining open and being viewed as a health service.

While the CNA has official nursing policy and positions in support of harm reduction, many health care organizations do not have organizational harm reduction policies. This lack of policy can be a key source of ethical tension for nurses, requiring advocacy, education, and policy making.

Harm reduction is also a philosophy and set of principles that are integral to ethical nursing practice. Harm reduction as a context for ethical nursing practice means shifting moral values in order to develop trust and relationships so that nurses do not judge or label people for their drug use, but rather provide respectful and non-judgmental care while taking action at other levels to counter stigma and discrimination (Iammarino & Pauly, 2020; Pauly, 2008b; Pauly, 2014a). The use of harm reduction often falls short of addressing the full range of health and social inequities, and thus should be viewed through a social justice lens in which there is attention to the SDOH (Pauly, 2008a; Pauly et al., 2013).

**Trauma- and Violence-Informed Care**

Browne et al. (2018) have highlighted the importance of trauma- and violence-informed care as part of equity-oriented care alongside cultural safety and harm reduction. They pointed to the importance of understanding that trauma is structurally produced and as such, nurses should recognize trauma as a context for providing care without necessarily having knowledge of specific traumas. Such
sensitivity can guide nurses to align with ethical approaches in the provision of care. However, this requires deep and ongoing attention to and understanding of the structural conditions that cause harm, how nurses can be implicated in that harm, and the potential for the work of nurses to unintentionally cause harm. EQUIP Health Care provides multiple resources for integrating equity-oriented care into nursing and health care practice (EQUIP, n.d.).

**Conclusion**

Health equity and addressing ongoing historical and structural inequities is complex within systems that do not prioritize health equity and are bereft of a focus on the SDOH. As a result, individual actions and advocacy, in combination with systemic shifts, are needed desperately. For individual nurses, recognizing racism, stigma, and discrimination that threaten health equity can help to mitigate daily injustices that mediate access to health care. Such individual actions have a meaningful impact, especially when nurses challenge daily practices and local policies in their workplaces and communities. Nurses collectively have a critical role to play—and crucial contributions to make—in the fight for global shifts in thinking that elevate health equity as a true priority, rather than just a stated one, in health and social systems. In particular, as leaders in health care, advanced practice nurses are especially well-positioned to support enhanced education, policy, and program development that can help to promote health equity and address the root causes of inequities.

**QUESTIONS FOR REFLECTION**

1. *What are health inequities and how are health inequities produced?*

2. *What is the role of advanced practice nurse leaders in addressing health equities?*

3. *What might nurses draw from theories of social justice that could inform their practice and enhance social justice in health care?*
Endnotes

1 For a comprehensive description of the challenges in public health, refer to Chapter 4 in this book.

2 Vancouver’s Insite, opened in 2003, is North America’s first sanctioned supervised drug injection site. Drug users can inject illicit drugs there because Insite has a federal exemption from Health Canada. In addition, Insite provides clean equipment for drug injection, spectrometer testing of drugs, immediate overdose response, clinical care, and connections to health care and community services (PHS Community Services Society, n.d.).

References


Canadian Drug Policy Coalition. (n.d.) *History of drug policy in Canada.* https://drugpolicy.ca/about/history/


EQUIP Health Care. (n.d.). *What is health (in)equity and why is it important?* Canadian Institutes of Health Research. https://equiphealthcare.ca/about/


ONE COMMONLY CITED STATISTIC ON HEALTH in Canada is that approximately 20% of Canadians will experience mental health or substance use issues in their lifetime (Canadian Alliance on Mental Illness and Mental Health [CAMH], 2021). While these challenges occur across all levels of socio-economic status, Canadians in the lowest income groups are three to four times more likely to experience mental illness and substance use issues (CAMH, 2021), reminding us that a greater proportion of the burden of illness is borne by those with fewer resources.

“[M]ental health and substance use health needs are significant and both continue to be orphans of our publicly-funded health care systems when compared to the care we provide for peoples’ physical health.” (Canadian Alliance on Mental Illness and Mental Health, 2021, p. 6)
Throughout Canadian history, governments have made decisions that ultimately embedded the causes of inequity in mental health care services directly into health care structures. These decisions were rooted in a particular constellation of social, political, and economic philosophies that continue to shape social policy at local, provincial, and national levels (Morrow, 2009). Advocacy for patient care is foundational to practice in health care professions such as nursing and social work. Advocacy directed at a level of the system where individual health care providers (HCPs) do not have the authority to respond to the request may leave HCPs feeling disheartened and powerless, contributing to the experience of burnout, compassion fatigue, moral distress, and moral disengagement (Rodney et al., 2013). Equipping nurses with knowledge about the history and structures that have created and sustained inequity is crucial to promoting effective advocacy for true systems change.

Our goal in this chapter is to present a case for equitable access to quality mental health care, and to provide nurses with an understanding of barriers to equitable access across levels of the health care system, as prerequisite to effective advocacy and leadership. Thus, we have chosen to focus our attention on these structural underpinnings rather than simply highlighting the numerous ethical challenges that nurses in mental health contexts face on a daily basis. To accomplish this, we begin by introducing concepts taken up by politicians and implemented in ways that create and sustain barriers to adequate funding of the mental health care system and access to mental health services. Central concepts we analyze include neoliberalism and stigma. We discuss the ways neoliberal ideology and stigma are embedded in policies at multiple levels and applied in ways that perpetuate unjust and avoidable barriers to high quality mental health care. Application of these policies contributes to poor outcomes in mental and physical health for people with lived experience of mental illness and substance use. We connect ethical challenges that HCPs confront to policy informed by economic values that conflict with professional values. We also highlight the role of advanced practice nurse leaders in interdisciplinary team-based approaches to addressing the gaps in mental health services. Further, we use Ethics in Practice situations
to explore the complexities and subtleties of stigma and economic barriers to care. We end with practical recommendations that advanced practice nurses (APNs) and other HCPs can take up as they address inequities at micro, meso, and macro levels of health care.

**Defining Equitable Mental Health Care**

In making the case for equitable and high-quality mental health care, we look to research, practice, and policy leaders such as EQUIP Health Care¹ and the Mental Health Commission of Canada (MHCC) for important definitions and frameworks. The EQUIP Health Care team includes interdisciplinary researchers, knowledge users, and health care partners working together to develop health equity interventions across a range of settings. The EQUIP team provides clear definitions of the key terms “health equity” and “health inequity” that we use in this chapter:

Health equity is defined as the absence of avoidable or modifiable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. Health inequities are unjust and avoidable, and represent unacceptable differences in health between and within groups of people. (EQUIP, n.d., emphasis original)

**Influence of Historical Funding on Mental Health Care Services**

The Organization for Economic Co-operation and Development (OECD) recognizes mental illness as one of the fastest-growing categories of the burden of disease in the world (OECD, 2014). In 2021, the Centre for Addiction and Mental Health (CAMH; n.d.) identified the overall cost of mental illness in Canada as approximately $51 billion dollars per year. Further, the MHCC (2017) provided estimates of the prevalence of mental illness in Canadians across age groups:
In 2016, more than 7.5 million people in Canada are likely facing one of the common mental illnesses—which is one in five Canadians, or more than the population of our 13 capital cities combined…. Among people under the age of 65, mental illness makes up approximately 38% of all illness. (p. 8)

However, Canada allocates approximately 7.2% of its total health budget to mental illness (Bartram, 2017; CMHA, 2018). The discrepancy between the limited allocation of funding for the mental health system and the actual burden of mental illness in Canada reflects a reluctance to fund mental health care that has existed from the inception of universal health care in Canada. We contend that many of the ethical challenges experienced today in mental health care have arisen from historical underfunding and subsequent fragmentation of mental health services. To address ongoing issues of underfunding, it is important to understand the mechanisms that established and now maintain the unequal distribution of health dollars. In the next section, we outline the funding relationship between the federal government and the provinces and territories as one of the sources that perpetuates inequities in mental health care services.

Federal, Provincial, and Territorial Funding Relationships

Entrenched in Legislation

The federal, provincial, and territorial governments of Canada formally launched universal health care in 1957 as the Hospital Insurance and Diagnostic Services Act (HIDS Act). The HIDS Act laid out specific criteria for cost sharing between the federal government and the provinces and territories for medically necessary services delivered by physicians or services delivered in hospitals. The Act also limited care for mental illness in acute care hospitals to 10% of the overall beds (Bartram & Lurie, 2017; Wiktorowicz et al., 2020). The decision to exclude mental institutions from federal funding was widely criticized at the time as being a heavy financial burden on the provinces and territories, given that “68,000 beds in uninsured mental hospitals comprised nearly half of hospital beds in Canada at
The time” (Bartram & Lurie, 2017, p. 8). The federal government’s unwillingness to integrate mental health care into universal health care was debated in the House of Commons in 1957 and seen as a “discriminatory evasion of responsibility” (Wiktorowicz et al., 2020, p. 3). It is important to note that these early attempts to limit financial responsibility for mental health care services, stigma, and jurisdictional politics laid the foundation for the gaps in services we struggle with today, and continue to threaten “meaningful progress” on closing these gaps (Bartram & Lurie, 2017, p. 13).

The legislation related to mental health has evolved over time and is included in the Canada Health Act (CHA) (Government of Canada, 1985). Since the 1970s, the federal government has backed away from the original cost-sharing agreement of 50% of provincial and territorial total health insurance costs. As the federal share of the costs decreased, provincial and territorial governments gained greater autonomy over how the money is spent (Bartram & Lurie, 2017). The provinces and territories are required to meet the five criteria of the CHA—universality, comprehensiveness, public administration, portability, and accessibility—to be eligible for shared funding. As long as the provinces and territories adhere to the CHA criteria, they have independence in determining the distribution of federal funding for health care services.

Consequently, community-based services—such as mental health and home care,3 for which funding falls within the sole purview of the provincial and territorial governments—are constrained by the prevailing financial climate of the province or territory. Separating the source of funding (the federal government) from those who make decisions about resource allocation (provincial and territorial governments) creates challenges for effective advocacy. When advocacy groups lobby the federal government for specific services, the federal response is often to deflect back to provincial and territorial decisions on resource allocation. Yet, if these groups lobby at the provincial or territorial level, these governments deflect upwards, claiming that they are not adequately funded by the federal government. Without designated funding, no level of government is actually held accountable for decisions about resource allocation (Wiktorowicz et al., 2020).

From the inception of the universal health care system in Canada,
mental health services have been inadequately funded. The gap in funding mental health services created by the CHA has never been closed (Bartram & Lurie, 2017).

Legislators outlined the funding relationship between the federal government and HCPs in the CHA. In the CHA, physicians are recognized as the only HCPs authorized to provide medically necessary treatments. Therefore, physicians alone are able to access guaranteed federal funding through fee-for-service mechanisms. The long-term consequences of embedding this funding structure into legislation continue to reverberate today. Other HCPs, such as advanced practice nurses (APNs), social workers, and psychologists working in the community, require direct funding from the provincial government or direct payment from patients. Hence, access to a wider variety of treatment providers is limited for those who cannot afford to pay out of pocket. This discrepancy establishes a de facto two-tiered system for accessing effective, comprehensive mental health services.

Many of the ethical challenges we confront today in mental health care, such as a lack of effective treatment options and long waitlists, result from governmental attempts to mitigate financial responsibility for health care. The CHA’s five criteria of public administration, comprehensiveness, universality, portability, and accessibility are the stated values which have been regularly affirmed by Canadian citizens. Yet, decisions on constraining health care costs are often rooted not in these stated values, but in political concerns and economic influences (Morrow, 2009).

**Influence of Neoliberalism on Mental Health and Mental Health Care Services**

Government spending, and constraints on spending, are determined by both internal (national) and external (global) forces. Internal factors include the funding structures discussed above. External factors that shape government spending, such as global economic forces, impact the Canadian economy. Socio-political and economic ideologies used by decision makers to frame policy decisions at the macro level are distant from actual service delivery, yet they have a profound impact on determining which services will be delivered at...
the micro level and how these services will be implemented (Bartram & Lurie, 2017). Therefore, HCPs ought to have an awareness of the past and present factors that influence allocation decisions in order to knowledgeably navigate, and ultimately ameliorate, ethical challenges that arise from structural causes.

Globally, since the late 1970s, the tenets of neoliberalism have underpinned discourses and subsequent policies in health care delivery. We define neoliberalism as an economic model in which the market is considered to be the most reliable framework for guiding all human activities. In assessing the impact of neoliberalism on mental health care, we used Steger and Roy’s (2010) description of neoliberalism as having “three intertwined manifestations: (a) an ideology, (b) a mode of governance, and (c) a policy package” (p. 11). To their aspects of neoliberalism we add two of our own: deinstitutionalization and the influence of the drive for efficiency.

**Ideologies**

Ideologies are a shared set of beliefs and ideas that a group holds to be true. These beliefs are value-laden and so deeply embedded that they are often unspoken and operate at a level outside of our awareness (Browne, 2001; Steger & Roy, 2010). Ideologies can also be insidious, colouring our perspectives and how we view others. It is through self-reflection and critical examination of policies that we become aware of how ideologies influence decisions at the micro, meso, and macro levels of health care delivery. Those who adhere to neoliberal ideologies have supported a shift towards primarily a biomedical approach in the treatment of mental disorders. This neoliberal approach is consistent with the Canada Health Act, where health services are limited to those provided by physicians (CMHA, 2018; Esposito & Perez, 2014). We further address the impact of neoliberalism on mental health care policy below.

**Governance**

Social policies are developed and implemented within systems of governance. A definition of governance is how a nation or organization is governed, or, more simply, how decisions are made, including who gets to participate in decision making (Institute on Governance, 2021). Those developing effective government
frameworks, particularly strategies to address mental health, need to attend to the social context in which inequities are embedded (CMHA, 2018). Historically, decision making at meso and macro levels has reflected a paternalistic top-down approach. More recently, we have observed the threads of collaboration and inclusivity running through publications by advocacy groups, and government policy documents calling for consultation with a broader range of stakeholders. For example, a core value of the MHCC (2021) strategic mental health plan, “build a bigger table” (p. 16), incorporates a diverse range of voices with experience of mental health issues in the development of mental health policy and tools.

**Policy Packages**

The uptake of neoliberal ideology has contributed to widening social and economic inequities through the application of market values to social policies. Social policy refers to government policies directed at meeting the needs of the population, often referred to as welfare needs (Scott & Marshall, 2009). Social policies strengthen social programs responsible for supporting human flourishing, and include social assistance, health, education, and housing. These areas encompass the social determinants of health (SDOH), which have been directly correlated with rates of mental illness. Steger and Roy (2010) described the rise of neoliberalism as a global economic model, finding that all countries which adopted neoliberalism experienced a rise in inequities in the SDOH.

Efforts to contain health care costs regularly rely on business models that are uncritically imposed in health care processes without consideration of how these models create practice environments that conflict with core values of HCPs. Below, we focus on deinstitutionalization and a drive for efficiency as examples of how neoliberal ideologies contribute to ethical challenges in mental health care.

**Deinstitutionalization**

In the 1980s and 1990s, mental health system reform included the deinstitutionalization and application of market principles to health care organizations. The arguments for deinstitutionalization were premised on reports that detailed the deplorable conditions and
overcrowding in asylums (Hall, 1964). In a Canadian study, Morrow (2009) examined the intersection of neoliberal ideologies, restructuring of social programs (including health care), and mental health reform in the context of deinstitutionalization. Morrow highlighted that mental health policy is “intimately connected to economic decision making” (p. 40). Morrow situated this critique in the broader context of globalization and social welfare restructuring, where it became more difficult for people with mental illness to access social supports such as “social assistance, public housing, and a whole range of community-based supports” (p. 41). Such difficulties have had several consequences for people discharged from mental asylums. Inability to access social services, such as housing, contributed to increased homelessness for individuals with mental illness, and increasing pressure on acute care services, resulting in a “revolving door syndrome” (Morrow, 2009).

Social welfare reform impacted deinstitutionalization in other ways, as provincial and territorial governments, which have sole jurisdiction for mental health funding, curtailed funding of community mental health services. The potential for more humane treatment of individuals with mental illness through community-based treatment and support was not realized, because the money spent on mental institutions never shifted to community services (Lurie, 2014; Read, 2009; Wiktorowicz et al., 2020). Read (2009) underscored the failure of deinstitutionalization in British Columbia (BC) with the closure of the provincial mental hospital, explaining that monies intended to fund community-based support were never reallocated for community-based programs. Development of policy initiatives that resulted in closure of inpatient treatment facilities, while at the same time decreasing overall funding for community-based services, was not isolated to BC. For example, Bartram and Lurie (2017) outlined a similar occurrence in Ontario in relation to deinstitutionalization.

**Influence of the Drive for Efficiency**

While efficiency in health care—seen as a combination of quality services and numbers served—is a core value in market-driven systems, measuring improved efficiency is difficult. Such measurements are often limited to the quantification of tasks (Austin, 2011)
and a focus on the costs of services (Kyeremanteng et al., 2019). An example of policy implemented by the provincial governments in attempting to improve quality and efficiency is the introduction of pay-for-performance initiatives (P4P) in Canada (Cheng & Sutherland, 2013). P4P initiatives were introduced into the Canadian health care system in the mid-2000s in an effort to mitigate rising costs and improve the quality of care through the use of evidence-informed practice guidelines (Kyeremanteng et al., 2019). Although a range of P4P incentives currently exists in Canada, the effectiveness of incentive programs in achieving the identified goals is mixed (Cheng & Sutherland, 2013). Financial incentive programs raise unintended ethical pitfalls for HCPs that are difficult to surmount unless they are explicitly addressed in the planning phase and throughout the programs. Ethical pitfalls include the avoidance of patients with complex health issues due to inadequate financial reimbursement for physicians through the fee-for-service model; challenges with measuring outcomes for complex patients; and a focus on outcome scores, rather than the actual patient experience (Kyeremanteng et al., 2019). These pitfalls contribute to increasing inequity in access and quality of care. In Ethics in Practice 10-1, we provide a case study of a P4P initiative for review.

**ETHICS IN PRACTICE 10-1**

*Pay-4-Performance in the Emergency Department*

In 2007, the Ministry of Health in BC introduced P4P initiatives in the emergency departments (EDs) of several urban hospitals to see if these initiatives would help decrease wait times for patients while maintaining quality of care. Mindy, a psychiatric liaison nurse, is aware that the hospital will receive financial incentives if patients are seen within recommended time frames based on the Canadian Triage Acuity Scale (CTAS).

Since the P4P initiative was introduced, Mindy has noted some changes in her team’s actions, including the need to move people through the ED quickly. Several nurses on her team are doing very brief, sometimes incomplete assessments on presenting patients. Mindy has observed these nurses using information from previous encounters to fill in the assessment forms of patients who are in the ED regularly. She has also noted that when a nurse takes more time with a patient, some colleagues question their competence in completing an assessment. When Mindy questions these
Governments have taken up a mantra of improving efficiencies as one of the measures to decrease costs. While improving efficiencies can be effective in decreasing spending and improving quality, without thoughtful consideration of how efficiency is being envisioned and measured in health settings, efficiency foci can contribute to values conflicts for direct care providers.

Our purpose in beginning with a discussion on neoliberalism is to make the connection clear between economic ideologies and subsequent health care policies that contribute to or create ethical conflicts in clinical practice. As we move forward in this chapter, we

-criticisms, she is told that “an efficient nurse can complete an assessment in 10 minutes.” As well, once a patient is triaged, they are moved out of the waiting area and into the treatment area, so that it looks like no individual is waiting to be seen. This practice has led to overcrowding in the psychiatric space, increasing the potential for aggression from patients in acute distress.

Mindy has also observed a disturbing trend in which more complex patients, such as individuals with a concurrent disorder, a history of trauma, or a dual diagnosis, are being deflected out of the ED by some members of her team. Finally, Mindy has noticed that individuals presenting in the ED with physical complaints, but who also have an existing psychiatric diagnosis, are being under- triaged and directed to the psychiatric area of the ED. On her last shift, a patient with a fentanyl overdose was admitted to the medical area of the ED. Shortly afterwards, the patient’s CTAS score was downgraded so they could be transferred to the psychiatric area. Tragically, the patient later died in the seclusion room from the effects of their overdose because the psychiatric area had minimal medical equipment.

REFLECTIVE QUESTIONS

As you think about Mindy’s experience and observations, consider your own practice environment and reflect on the following questions:

1. How is the need for efficiency and quality care balanced in your clinical area?

2. Are you aware of any P4P initiatives in your organization?

3. What are some of the consequences in your practice area that result from the need for efficiency being taken up uncritically?

4. What leadership initiatives could advanced practice nurses promote to improve the quality of care for people in EDs with mental illness?
highlight the synergistic relationship between stigma and neoliberal policies. Neoliberal policies alone do not account for the political reluctance to include mental hospitals in universal health care. Early on in the process of negotiating universal health care, stigmatizing attitudes towards mental illness played a key role in limiting funding for mental health (Bartram & Lurie, 2017; Wiktorowicz et al., 2020).

**Impact of Mental Illness-Related Stigma**

Stigma, as a concept applied to those with mental disorders, is pervasive, and has a long history. Our understanding of the stigma deeply embedded in our political and social structures has grown, and we now see stigma as a central barrier to equitable access to services (Livingston, 2013). Yet, increasing awareness alone has not contributed to positive changes in resource allocation or greater integration of services. Below, we provide a brief history of stigma and outline our current understanding of the concept. The MHCC has conducted extensive work on the concept of stigma in order to develop strategies and tools to address it. Because of this leadership, MHCC’s work is central to our discussion and recommendations for change.

**Stigma and Mental Illness**

Stigma is a phenomenon that is constructed psychologically and socially (Arboleda-Florez & Stuart, 2012). We use the definitions and descriptions of stigma put forth by the MHCC, as they capture a current and nuanced understanding of the experience and consequences of stigma at individual, interpersonal, and structural levels, while also accounting for the impact of intersectionality (Livingston, 2020). The MHCC explains:

> [Stigma] is first and foremost a social process that aims to exclude, reject, shame and devalue groups of people on the basis of a particular characteristic. … Therefore, stigma reveals more about society than it does about individuals who carry stigmatized characteristics or persons who harbour negative beliefs about others. (Livingston, 2013, p. 6)
With respect to mental illness, the roots of stigma go back centuries in Western discourses. From descriptions of madness in ancient Greek texts to the persecution of “witches” in Christian cultures in Europe and North America, stigma has evolved and changed, and has carried various religious and moral associations over time (Arboleda-Florez & Stuart, 2012). Despite a more nuanced modern understanding of mental illness as influenced by complex biological and environmental factors, shadows of earlier belief systems can be found in our current discourse.

**Influences of Stigma on Mental Health Services**

In the following sections, we discuss stigma at the individual, interpersonal/social, and structural levels as a foundation for discussing recommendations to lessen the negative impacts of stigma across these various levels. Since stigma impacts a person’s self-concept, as well as their interactions with HCPs, health systems, and society at large, solutions must take this full range of experiences into account.

**Self-stigma**

For those living with mental illness, internalized or self-stigma is a set of negative beliefs about oneself, alongside lived experiences that solidify these beliefs. Self-stigma often includes shame and acceptance of the idea that mental illness is less valid than other health issues, often resulting in a sense of isolation, low mood and low self-esteem, and a limited sense of autonomy (Henderson et al., 2016; Livingston, 2013). These negative self-beliefs are frequently reinforced by stigmatizing experiences in the community and when seeking health care, leading to individuals fearing and avoiding engagement with HCPs and support systems. Because mental illness influences mood, cognition, and behaviours, a person’s identity is at risk of being superseded by their condition. This fusion of illness with identity complicates attempts to effectively advocate against stigma because those with mental illness “risk having their resistance disregarded, silenced, and pathologized (e.g., ‘she’s angry because she’s not taking her medications,’ or ‘his personality disorder causes him to act out’)” (Livingston, 2013, p. 8).
Interpersonal or Social Stigma

Mental illness and substance use challenges are just two facets of identity for which a person may experience stigmatization. Stigma and discrimination are also directed towards racial and ethnic identity, gender, sexual orientation, socio-economic and educational status, and health conditions such as HIV, among other stigmatized characteristics or identities. Intersectional stigma refers to the ways individuals or groups experience the negative impacts of having multiple stigmatized identities. Many people with mental illness face the compounded challenges of intersectional stigma as they attempt to access care (Turan et al., 2019).

Numerous reviewers of the literature point to a pattern of problematic interactions between HCPs and those with lived experience of mental illness and substance use. As Knaak et al. (2017) described, “people with lived experience of a mental illness commonly report feeling devalued, dismissed, and dehumanized by many of the health professionals with whom they come into contact” (p. 111). Stigma enacted by HCPs may manifest as having demeaning or paternalistic interactions with patients, giving limited or incomplete information regarding diagnoses and treatment options, or using the threat of coercive treatment to steer plans of care. Further, many providers lack confidence in the efficacy of interventions for mental illness and substance use challenges. This “therapeutic pessimism” often creates a self-reinforcing negative cycle where providers are not confident of a positive outcome, and thus withhold or limit access to potentially helpful treatment options (Knaak et al., 2017). For people who have multiple stigmatized identities—for example, a racialized person without stable housing experiencing a mental illness—intersectional stigma can significantly and negatively impact both mental and physical health outcomes (Turan et al., 2019).

Structural Stigma

Mental illness-related stigma at the structural level has perhaps the most profound impact on equitable provision and accessibility of health care. Health care systems have been consistently identified as contributing to and reinforcing structural stigma by limiting access
and rendering poorer quality services to those with mental health and substance use issues. The MHCC points to three key challenges to equitable access to care for those with mental illness and substance use issues: (a) under-resourcing of services; (b) de-prioritization, under-treatment, and denial of service; and (c) separation of mental health, substance use, and physical health services (Livingston, 2020).

Under-resourcing manifests in many ways, including chronic governmental underfunding of resources to support services for, and research about, mental illness and substance use issues relative to their burden of disease. Under-resourcing also manifests as lower reimbursement rates for mental health care services by both publicly funded and private health insurers. Under-treatment and de-prioritization in the form of diagnostic overshadowing is common when those with mental illness and/or substance use issues present for health care (Henderson et al., 2014). Overshadowing happens when HCPs minimize or neglect the physical health concerns of people with mental health and substance use challenges, which can lead to missed diagnoses, delayed care, and worse health outcomes.

In addition to inequitable access, structural stigma also leads to poorer quality of care. Stigmatizing attitudes and behaviours of HCPs, coupled with an over-reliance on coercive treatment, negatively impacts the quality of care received (Henderson et al., 2014; Livingston, 2020). Since HCPs shape the culture, norms, and practices of the systems where they provide care, their beliefs and actions directly impact structural stigma. In Ethics in Practice 10-2, we provide a case study on stigma.

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**ETHICS IN PRACTICE 10-2**

**Stigma**

Kate is a 30-year-old woman who belongs to a racialized group. She is a single mother who is on social assistance and lives in a subsidized housing complex. Kate presents at the mental health centre for assistance with worsening mood and suicidal ideation. Kate has been previously diagnosed with depression, post-traumatic stress disorder (PTSD), and chronic widespread pain. She has a past history of polysubstance misuse; however,
she states that she has not used substances in the past three years. Kate’s elementary school-aged son has been diagnosed with fetal alcohol spectrum disorder (FASD). Kate often feels overwhelmed by his needs and challenging behaviour, which can also trigger her PTSD symptoms. She feels significant guilt and shame about his diagnosis. Kate has limited social supports and no extended family involvement due to her history of childhood trauma.

The mental health team offers psychiatry appointments and group therapy for depression. Kate was registered for a depression group in the past and there are a number of late cancellations and no-shows on her file. A note on Kate’s file states a “lack of follow-through.” The Mental Health Centre has now instituted a “three no-shows and you are out” policy. Although Kate is interested in group therapy, she struggles to attend the sessions due to the needs of her son. Kate’s son’s needs are under-resourced in the school system and Kate is often called to pick him up early. Kate knows that she could increase resources for him at school; however, it would require her to disclose the diagnosis of FASD to the school board. Kate also struggles to attend sessions when her pain levels are elevated. Kate is interested in specific therapy for PTSD but she has been unable to access this type of therapy in a free or low-cost setting.

REFLECTIVE QUESTIONS
As you think about Kate’s situation, consider your own practice environment and reflect on the following questions:

1. What assumptions might you make about patients who do not follow through with treatment?

2. How does your viewpoint change when you learn details of Kate’s context?

3. How has Kate experienced stigma at individual, interpersonal, and structural levels?

4. What policies exist in your workplace (such as the “three no-shows and you are out” policy) that may create barriers for patients who are already experiencing inequitable access to health care?

5. We suggest you watch the brief video Beyond Stigma (Subject Matter Lab Health Research Lab, 2021) (see References). After watching the video, consider how including the patient in a team approach can reduce stigma.

6. What strategies could an APN use to foster a person-centred approach to Kate’s situation?

We have argued that stigma and neoliberal ideology are intertwined. In societies influenced by neoliberal ideology, individuals
who are viewed as flawed are both inherently less valued and also left on their own to “fix” the parts of themselves that are deemed unworthy by society. Stigmatizing attitudes towards mental illness have contributed to the underfunding of mental health care in Canada’s universal health care system, and continue to pervade subsequent mental health care policy decisions. We have argued that in mental health care, neoliberalism and stigma at individual, interpersonal, and structural levels combine to (a) create barriers to accessing care; (b) contribute to poorer quality of care; and (c) cause poorer mental and physical health outcomes for people with mental illnesses and/or substance use challenges.

The COVID-19 pandemic may have unexpected benefits in addressing stigma for mental health care. As we discuss below, the pandemic has brought mental health promotion and prevention to the forefront of health discussions, particularly as we consider the impact of the pandemic on HCPs. In giving serious consideration to supporting the mental well-being of all Canadians, we need to maintain a level of critical awareness so that we do not create a two-tiered mental health response; that is, we do not want to create one response for individuals whom we might view as “like us,” who are struggling to manage chaotic external circumstances, and a second response for individuals struggling with chronic mental illness.

Changes to Mental Health Care Services

Over the past six decades, the federal, provincial, and territorial governments of Canada have sought to address gaps in mental health services. Below, we highlight some of the changes brought about by the work of the MHCC and other advocacy groups; comment on how the COVID-19 pandemic has impacted mental health services; and discuss the potential for APNs to address service gaps.

Mental Health Spending Parity

Several mental health advocacy bodies have noted the discrepancy in funding between mental health issues and physical health issues. The MHCC (2017) made the case for increased spending on the mental health system, stating that “the impact of mental health
problems and illness is more than one-and-a-half times that of all cancers” (p. 10). Yet, funding for mental illness remains well below recommended levels. Globally and nationally, there are increasing calls for parity in government health spending between mental illness and physical illness (Canadian Alliance on Mental Illness and Mental Health [CAMIMH], 2021; CMHA, 2018; Pan American Health Organization, 2018).4

**Addressing Inequity Through Increased Funding**

In 2017, the federal government moved to address funding inequities in mental health services by adding five billion dollars in targeted funding dedicated to improving mental health outcomes (Department of Finance Canada, 2017). The increased funding was to be directed towards improving community-based services, giving access to psychotherapies, decreasing wait times for services for young Canadians, and improving accountability in reporting on investments in the health care system. The added funding was an incremental step towards the MHCC recommendation that Canada increase mental health funding from 7.2% to 9% of the overall health budget to improve mental health outcomes through increased access to services (Bartram, 2017).

That same year, the federal government proposed an additional $204 million over five years to increase mental health services for First Nations and Inuit Peoples, expanding services to include a greater diversity of mental health professionals as well as Traditional Healers (Department of Finance Canada, 2017). However, increased funding will not improve inequities without the concurrent development of accountability frameworks and indicators in order to measure improvement in quality and access (Bartram, 2017; Follwell et al., 2021). In Ethics in Practice 10-3, we provide a case where we highlight the complexity of addressing inequities in access to services.
Addressing Inequities

Addressing inequities in access to mental health care services is complex, and requires more than added funding and increased services. Bartram (2017) pointed to examples of significant financial investment in mental health services in the United Kingdom (UK) and Australia. Enhanced funding was aimed at increasing access to services and improving client outcomes.

The Australian government amended their funding mechanisms so that individuals with mental health issues could access a broader range of mental health professionals (for example, psychologists), thereby improving access to services. Subsequently, the Australian government reported that treatment rates for individuals with anxiety, depression, and substance use rose from 38% to 46% (Meadows et al. 2015).

The UK developed a program called “Improving Access to Psychological Therapies” (IAPT) to decrease waitlists and improve access to services for people with common mental health problems such as depression and anxiety. Since initiation of the program in 2008, the National Health Service (NHS) in the UK reported strong overall outcomes, with 50% of the patients enrolled in the program no longer meeting the clinical criteria for depression and anxiety (Bartram, 2017). Significantly, a closer look at the statistics related to the use of enhanced services revealed that the greatest benefit of improved access to mental health services was experienced by the most socio-economically advantaged (NHS Digital, 2016; Meadows et al., 2015). In fact, in their examination of usage rates following the increase of mental health service providers in Australia, Meadows et al. (2015) stated:

These results are consistent with a multi-tier system, where people living in more disadvantaged and more rural areas will typically receive a service model in response to mental health needs that is characterized by lower volumes of services, provided possibly by less highly trained providers. (p. 193)

Meadows et al. (2015) and Bartram (2017) demonstrated that simply increasing funding or expanding services without attending to the inherent complexity that contributes to inequities—such as limited access to health care in rural/remote areas and complex chronic concurrent disorders—will not succeed in closing gaps in services.

REFLECTIVE QUESTIONS

Consider the following questions as you think about using increased funding to address inequities in access to mental health care services:

1. What inequities in access to mental health care services do you see in your area of practice?
Addressing Inequity Through Collaboration

Recognizing the importance of working collaboratively to improve access in two priority areas (home and community care, and mental health and addictions), the federal, provincial, and territorial (FPT) governments worked together and created *A Common Statement of Principles on Shared Health Priorities* to guide actions (Canadian Institute of Health Information [CIHI], 2017). The stated principles included collaboration between federal, provincial, and territorial governments; innovation; and accountability. Subsequently, the FPT governments and sector stakeholders worked with CIHI to develop indicators to measure the shared priorities. Indicators were developed across five themes: access, quality of care, spending, health promotion and disease prevention, and health outcomes. In 2019, CIHI began to report on additional indicators as they were being developed. Significantly, mental health advocacy groups and government agencies have recognized the importance of including people with lived experience (PWLE) of mental illness and substance use in the development of policy. These collaborations are important for developing mental health care policies that effectively address inequities.

Addressing Inequities Through Integrated Care Teams

Researchers have provided evidence connecting an integrated care approach to improved patient outcomes, decreased costs, shorter wait times for services, and shorter times in treatment, along with
other benefits (Durbin et al., 2016). Initiatives directed at greater integration of services through primary care teams already exist in Canada through Integrated Youth Services (IYS), meaning that mental and physical health and social care all occur at one location (Hetrick et al., 2017). This is one example of how an interdisciplinary team can address mental health issues in youth earlier to improve outcomes (Halsall et al., 2019). Another example of using an integrated care approach to improve health outcomes is seen in the way professional nursing organizations advocate for APNs to be deployed to improve access to health services in general, and mental health specifically, through the integration of NPs into community mental health teams (Kant et al., 2019). However, several barriers constrain expansion of interdisciplinary integrated care teams, including the funding model established in the CHA (discussed in the early section of this chapter entitled “Federal, Provincial, and Territorial Funding Relationships Entrenched in Legislation”; Durbin et al., 2016).

With the rapid rise in deaths related to the toxic opioid drug supply, APNs, such as NPs, are being asked to fill gaps in access to substance use treatment. However, limited education about mental health care serves as a barrier to NPs working with individuals who have mental illness and substance use challenges (Creamer & Austin, 2016; Kant, 2019). Addressing opioid use includes giving NPs (and registered nurses or registered psychiatric nurses in some provinces) the ability to prescribe methadone and buprenorphine-naloxone—medications used in the treatment of opioid use disorder (OUD)—and education about these drugs. In a recent study, researchers in Nova Scotia highlighted that NPs felt uncomfortable prescribing methadone due to a lack of education about mental health care and limited practice support (Bates & Martin-Misener, 2021). Such barriers are particularly detrimental for NPs working with individuals who have mental illness and substance use challenges (Creamer & Austin, 2016; Kant, 2019). Patients at highest risk for overdose death were also navigating the impacts of trauma, mental illness, poverty, and other related challenges (Tyndall, 2020). NPs and HCPs prescribing opioid agonist treatments, therefore, need additional education in mental health care and more comprehensive supports to provide adequate care for the whole person.
In response to the challenges noted above, Project ECHO (Project Extension for Community Health Care Outcomes) is being implemented in provinces and territories across Canada to improve health outcomes for Canadians, particularly in underserved populations. Project ECHO is an interdisciplinary, virtual, case-based learning community. Providers can bring complex patient presentations for discussion and care planning, learn from each other, and increase their capacity to care for these complex patients. Project ECHO has been effective in improving provider competence, changing provider practice, and improving outcomes (Sockalingam et al., 2018).

Other suggestions to support APN education in mental health and substance use treatment include intensive clinical experiences for HCPs, with early exposure to treatment for addiction, ongoing clinical supervision, workshops, attending interdisciplinary rounds, and the development of a formal specialty role for NPs in mental health care (Bates & Martin-Misener; Kant et al., 2019). Additionally, an APN can join an Adaptive Mentorship Network (see Appendix 10-1) designed to connect health care provider mentees with mentors in a supportive networking environment with group-based mentoring and learning opportunities, and on-demand one-to-one mentoring conversations. The networks are intended to build knowledge, skills, and resiliency of HCPs, while also developing capacity to meet the needs of complex patient populations.

**Ethical Challenges and Opportunities Arising From the Pandemic**

Notwithstanding the progress we have noted above, the COVID-19 pandemic has exposed the gaps in mental health care as countries imposed varying degrees of restrictions to limit the spread of SARS-CoV-2. Restrictions included a rapid reduction of support services for individuals involved in the mental health care and substance use system (CCSA, 2020). While the full impact of pandemic measures on those living with mental illness is not yet known, researchers highlighted the disproportionate impact of the pandemic on populations experiencing pre-existing health and social inequities (CMHA, 2020; MHCC, 2021). The most enduring consequences of the pan-
demic have been the psychological trauma, mental illness, economic injury, and burnout it has fuelled (Tseng, 2020). In Canada, the impacts of these traumas have been particularly evident in HCPs, as indicated by their increasing requests for mental health services and a rise in substance use (CMHA, 2020). This has prompted federal, provincial, and territorial governments to fund initiatives that support the mental well-being of HCPs and frontline workers.

Governments at all levels have moved quickly to upscale service initiatives that already existed in mental health; for example, tele-health, virtual health care, and mental health apps (Moreno et al., 2020). Ethical concerns regarding equitable access to technology, technological proficiency, privacy, confidentiality, funding, and evidence of quality need to be considered as these initiatives become part of ongoing practices. Given the rising cost of service delivery, HCPs need to attend to the warning that “[l]ow-quality mental health care based on affordability without assessment of quality or monitoring of needs and efficiency will only contribute to increasing inequalities and worsening mental health globally” (Moreno et al., 2020, p. 820).

**Recommendations**

The issues that we have described throughout this chapter create, magnify, and reinforce multiple complex challenges to delivering equitable, high-quality mental health care. Multi-pronged, collaborative, inclusive, and sustained efforts towards improvement are needed. Understanding the intersection of politics, economic ideologies, and societal values facilitates knowledgeable action at all levels of the health care system. Evidence also supports the importance of collaboration and inclusiveness in improving mental health outcomes (CMHA, 2016).

Working in any part of the mental health care system can feel overwhelming for health care providers, given limited resources and the complexity of the issues. However, we believe that all efforts to move towards equity and quality in mental health care are valuable. We present the recommendations below so that each HCP can decide which levels of action they want to take. Being aware of the available resources and the range of mental health advocacy groups
may decrease the sense of isolation HCPs experience. Further, knowing the appropriate level at which to direct advocacy efforts increases the possibility of success. Our recommendations are, therefore, directed at action and advocacy for mental health policy and practice at micro, meso, and macro levels. Mental health advocacy groups have developed excellent resources for issues at all levels of the system (see Appendix 10-1 for a list of online resources).

**Micro Level**

We encourage APNs and mental health practitioners to

- use evidence-informed literature and policy briefs for self-reflection on how their own beliefs and assumptions inform their practice;
- seek out the perspectives of people with lived experiences of the services provided and reflect on how the actions of APNs and mental health practitioners influence their experiences;
- share their learning with colleagues to promote discussions of current policies and practices in their clinical settings;
- organize regular patient discussions/rounds where all professionals involved can meet to discuss specific complex patient situations;
- involve patients/clients in care planning to foster an understanding of their priorities as well as an understanding of what they perceive as barriers; and
- seek out mentors in specific practice areas to decrease individual providers’ sense of isolation in practice, including through an Adaptive Mentorship Network.

**Meso Level**

APNs, HCPs, and leaders can

- seek out and participate in ongoing education in mental health and substance use, regardless of their area of practice or specialty, as mental health and substance use can impact anyone in their care;
- join a Project ECHO;
• include PWLE on practice and policy committees;
• use evidence-informed research, integrated reviews, policy briefs, and toolkits to inform organizational policy and clinical practice;
• incorporate more content related to mental health and substance use into the curricula for APNs and other HCPs;
• include community stakeholders and patient partners in health care unit and organizational policy discussions;
• support interdisciplinary opportunities for learning together and sharing clinical approaches, including team case consultation;
• lead and participate in quality improvement initiatives, or research on interventions in mental health care; and
• consider how practices and policies in specific practice environments (for example, the need to call ahead and confirm appointments, or missed appointment policies) may create barriers to health care access.

Macro Level

APNs, HCPs, and leaders can

• foster interprofessional, interagency, and interprovincial collaboration to advocate for parity in spending for mental and physical health;
• use evidence-informed research to advocate for changes in policy directed at resource allocation on a population level (see Appendix 10-1 at the end of this chapter);
• become involved in local, provincial, or national professional associations, and engage in related interprofessional writing; including, for example, blogs, policy briefs, and opinion pieces for the media; and
• advocate for recognition of mental health as a health care specialty, and for provincial and national funding for educational programs specific to mental illness, substance use, and concurrent disorders.
Conclusion

It is important to recognize that working in any part of the mental health care system can feel overwhelming, especially given limited resources and the complexity of the issues being faced. In this chapter, we presented recommendations to encourage APNs and other HCPs to consider key actions to advocate for change. Being aware of available resources, such as mental health advocacy groups, can also decrease the sense of isolation APNs and other HCPs may experience. Knowing the appropriate level at which to direct advocacy efforts will increase the possibility of success for APNs and other HCPs, building a sense of competency that can lead to progressive change in mental health care from individual to systems levels.

QUESTIONS FOR REFLECTION

1. How do you see impacts of neoliberal ideology and stigma affecting mental health care in your practice or educational settings?

2. Considering the recommendations, which level of advocacy and action seems most feasible to you right now? What are immediate actions you can take?

3. What are some of your future goals for advocacy?
Endnotes

1 EQUIP stands for Equipping Health & Social Services for Equity. EQUIP Health Care is a broad program of research that brings together a range of stakeholders. The emphasis is on implementing interventions, across health care settings, which build organizational capacity to provide equity-oriented health care.

2 See Chapter 3 in this textbook for a more detailed discussion of the historical implications of how mental health care was funded.

3 See Chapter 13 in this textbook for a full discussion of home health care.

4 The calls for parity in mental health care spending have been around for a while but it is only more recently that they have gained traction. In Canada, the creation of the MHCC and their published work has elevated the importance of spending in mental health care. Globally, the pandemic has brought a higher level of credibility, and urgency, to the idea of parity in mental health spending.

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Online Resources for Mental Health

A Common Statement of Principles on Shared Health Priorities (CIHI, 2017)

From Out of the Shadows Into the Light … Achieving Parity in Access to Care Among Mental Health, Substance Use and Physical Health (CAMIMH, 2021)
https://www.camimh.ca/_files/ugd/b625ef_03591e97cob94f9af25c07b986e1c28.pdf


A Framework for Assessing Structural Stigma in Health-Care Contexts for People with Mental Health and Substance Issues (Livingston, 2021)

Project ECHO (n.d.) https://www.echocanada.net/

Adaptive Mentorship Networks

BC Adaptive Mentorship Network for Pain, Mental Health and Substance Use (Pain BC, n.d.) https://painbc.ca/adaptive-mentorship

CHAPTER 11

Health Equity, Reproductive Justice, and Relational Autonomy: Ethical Nursing Care for Childbearing Individuals and Families

Helen Brown and Kelly Gray

“[E]nhancing women’s power, choice, and control requires a shift in how nurses view women’s birth experiences and perinatal outcomes. These are not of women’s own making, but are shaped by the social, cultural, political, and economic contexts of care.”

(Brown et al., 2011, p. 113)
NURSES PROVIDE CARE to women and gender diverse people along a reproductive continuum of care that encompasses prenatal counselling, contraceptive education, abortion care, and in vitro fertilization (IVF). This continuum of care occurs during decisions to prevent, terminate, or continue pregnancies; during admission to the neonatal intensive care unit; and into the postpartum period for parents and newborns. Nurses require ethical knowledge to support optimal birthing conditions involving physicians, doulas, midwives, partners, and families, and they do so within the broader socio-political context of preconception care, pregnancy, birthing, and parenting.

Advancing equity in reproductive health and childbearing contexts is fundamental to the moral obligations and ethical values of nurses within acute, community, rural, and urban settings. Nurses are well-positioned, by virtue of their social justice mandate, to advance reproductive health policy and practice in partnership with childbearing individuals and families. In this chapter, we focus on how social justice and health equity can orient the ethical care of childbearing individuals and families. We also demonstrate how integrating knowledge about reproductive justice, as well as feminist perspectives on relational autonomy (Baylis et al., 2008; Sherwin, 1992), can be translated into both practice and advanced practice nurse leadership roles. We integrate two Ethics in Practice case studies to illustrate how these theoretical ideas can be enacted in everyday ethical nursing actions and knowledge for nursing leadership.

### A Social Justice and Health Equity Approach

At the heart of nursing practice and leadership is a social justice vision to achieve health equity through safe, ethical, and effective care. A social justice ethic in nursing was strongly influenced by the World Health Organization’s commission (WHO, 2008) on the social determinants of health (SDOH). The commission found that social injustice is a primary factor in health inequities: that is, unfair and avoidable differences in health status and quality of life are attributable to structural barriers’ and social disadvantage (WHO). The Canadian Nurses Association (CNA, 2010) defines social justice
as “the fair distribution of society’s benefits, responsibilities, and their consequences.” It affirms nursing’s commitment by viewing social justice as “means to an end and an end in itself” (p. 13), and highlights its alignment with nursing values set out in the code of ethics (CNA, 2010; CNA, 2017). In 2010, Cohen outlined four key actions to enact a social justice mandate in nursing: (a) being knowledgeable of evidence related to health inequities; (b) deconstructing societal beliefs that assume individual responsibility for health; (c) advocating for an equity lens in health policy and program planning within nursing contexts and organizations; and (d) working to bring about social change. Van Daalen-Smith (2019) eloquently captured nursing’s relationship to social justice:

To seek out and name injustices and inequities is nursing. To be a vocal advocate for fairness, non-maleficence and dignity is nursing. To call into question harmful policies, practices or assumptions that impede the health and quality of life of the planet and its inhabitants is nursing. Our legacy in equity-based concerns is rich, but our work is not done. Social Justice Nursing ensures that Canada’s nurses avoid complicity, keeping central to our work the inherent rights of the individuals, families, communities and populations we are privileged to care for and partner with. (p. 1, emphases in original)

Health equity has been a central focus for ethical nursing practice and leadership for some time. In 1992, Stevens urged nurses to take action to address barriers to accessing care and overall health and well-being, working from the critical knowledge that access to health care and health outcomes cannot be disengaged from socio-political contexts. Nurses using a health equity approach work from the assumption that inequalities or disparities in health status require analyses of social, economic, political, historical, and material contexts (Doane and Varcoe, 2021). Addressing these inequalities makes it possible to move beyond the predominant neoliberal emphasis on individual health behaviours to the broader set of social conditions and structural factors responsible for the unfair and unjust differences that produce health inequities. In
nursing, a health equity approach requires ethical values and commitments to social justice: equity aligns with fairness and justice, both in terms of access to health care and health outcomes. Using a health equity approach helps nurses turn their attention not only to the conditions and contexts that produce unfair and unjust differences, but also to calls for action about ameliorating and changing structures, conditions, and policy barriers in order to achieve socially just health care. We join other authors in this book in arguing for a shift from a traditional notion of justice (focusing on how to redistribute resources in health care), towards one where nurses consider the socio-political conditions and contexts that produce the distribution of resources. These socio-political conditions and contexts ultimately determine health differences or outcomes. Drawing on Young’s (2009) writings, we see the role of nurses as acting to change the conditions and contexts that impact unfair and unjust distribution of health care resources. This requires a focus on how power, agency, rights, and institutional relations influence equitable access to health care.

Considering our focus in this chapter is on childbearing individuals and their families, a health equity and social justice approach can assist nurses to enact their ethical obligations and provide nursing care across the continuum of reproductive health care and during childbirth and perinatal care. This means considering the broadest scope possible related to childbearing, childbirth, and reproductive health, while also deconstructing dominant social norms that create barriers to ethical care. One way nurses can take up this broad scope within their care is to challenge dominant gender norms as they relate to childbearing. For example, as Cohen (2010) argues, within maternity and perinatal care, childbearing is often aligned with biological sex and, when gender is considered, binary representations of gender are used (men/women).

Nurses provide care to women and gender diverse people along a reproductive continuum of care; from prenatal counselling, contraceptive education, abortion care, IVF, and during decisions to prevent, terminate, and continue pregnancies. Nurses are active in supporting optimal birthing conditions involving physicians, doulas, or midwives, and do so within the broader socio-political context of pregnancy, birthing, and parenting. Across this complex
continuum of care, we discuss in this chapter specific theoretical ideas and frameworks for ethical nursing practice and leadership that promote ethical and equitable care. We also focus on the role of nurses in reducing reproductive health inequities and promoting reproductive justice by specifically addressing how relationships, gender, and power intersect to shape the autonomy of women and gender diverse people during childbearing experiences.

Specifically, using a health equity approach helps nurses focus their analysis and action on the SDOH and contextual factors that shape maternal-infant outcomes. Nurses critically analyze policy and practice for impact on reproductive choices, decisions, behaviours, outcomes, and access to perinatal care. The SDOH (age, gender, ability, race, economic status, etc.) are also impacted by socio-political, historical, and economic factors that create and sustain unfair and unjust differences in reproductive health or childbearing outcomes. Taking both the SDOH and contextual factors into account means that nurses can situate specific experiences and realities of their patients in the broader context of their lives. For example, being a young mother is about more than age as a determinant of maternal health; it also about recognizing the historical, economic and socio-political factors that shape dominant norms and assumptions made about “young mothers” that can act as a barrier to accessing equitable and health-promoting care.

Using a health equity approach also means that nurses can ask questions such as how equitable reproductive and childbearing health outcomes can be achieved for all, while accounting for differences in peoples’ lives that matter (such as ability, experiences of trauma and violence, and racism). Using the health equity approach also turns nurses’ attention to what needs to change in order to support people in their life contexts at structural levels, such as in health care systems, policies, and practices. While nurses are oriented to these questions by using a health equity perspective, in this chapter we introduce a reproductive justice and relational autonomy framework to focus ethical knowledge and practices on promoting reproductive health equity for childbearing individuals and their families.
Reproductive Justice

The concept of reproductive justice has existed in the social sciences for almost 30 years, yet nursing has been slow to adopt this concept in promoting maternal-child health. In both Canada and the US, women’s health has tended to be conflated solely with childbearing. This has meant that less attention has been paid to the socio-political context of women’s health overall, and to the wider context of reproductive care and childbearing. For nurses providing reproductive and perinatal care, there is now greater attention being paid to questions about fair and just access, care, and health outcomes. Nurses are asking how they can act to change conditions and contexts that undermine reproduction, pregnancy, and birth. Notably, for over 20 years, Indigenous women and women of colour have been advocating for a reproductive justice framework. Such a framework is required to provide the knowledge and skills for promoting equity at interpersonal and system levels with regards to reproductive rights and advocacy (McKenzie et al., 2022; Shaw, 2013; Solinger, 2013). For Indigenous women and women of colour, a framework for reproductive justice can be used to emphasize interconnected and diverse rights, including the (a) right to have a child; (b) right not to have a child; (c) right to parent one’s children; (d) right to control birthing conditions; and (e) to advocate for the necessary enabling conditions to realize all of these rights (Shaw, 2013).

A reproductive justice lens is also grounded in intersectionality and interconnected human rights across the continuum of reproductive care, childbirth, and parenting (Ross & Solinger, 2017). Interlocking forms of social and structural oppression impact reproduction and childbearing experiences and access to care. Using a reproductive justice lens in practice helps to make visible particular people’s experiences and how these experiences are shaped by oppressive forces and conditions. It can also help nurses see how systems such as child welfare can facilitate or act as a barrier for people to either engage with or avoid social welfare and health care systems (Boyer & Bartlett, 2017; Denison et al., 2014). Using a reproductive justice framework enables public health nursing actions for racialized women, girls, and gender non-binary people by uncovering systems of oppression, recognizing past
historical injustices, and advancing cultural safety in health promotion. Nurses can become more attuned to how power, history, oppression, racism, and unsafe systems of health care contribute to childbearing and reproductive health outcomes.

**Relational Autonomy**

We now turn towards a discussion of how a reproductive justice and health equity lens can be translated into everyday ethical practices for nurses and nurse leaders in childbearing settings across the spectrum of care, from pre-conception to childbirth. We focus on the writing about relational autonomy by feminist bioethicists such as Sherwin (1992, 1998). Their work translates the theoretical concepts of reproductive justice, equity, and feminism into nursing practices to support the decisions of childbearing individuals as they journey through the myriad experiences from pre-conception to childbirth.

Beauchamp and Childress (2013), in their principle-based approach to bioethics, referenced the “ideal patient” when applying the principle of autonomy. In their view, this patient is seen as a standard reference point, but they did not consider the uniqueness of peoples’ contexts and histories; as nurses know, no such ideal patient exists. Nurses provide care to patients who differ drastically from the “ideal patient” Beauchamp and Childress described. There are, instead, patients who are unique and bring their lived experiences, histories, social and communal values, and expectations with them to each encounter.

Feminist philosopher Sherwin (1992, 1998) questioned the idea of an “acontextual patient” and developed the term “relational autonomy” as a way to understand the complexity of the concept of autonomy. In Sherwin’s view, context is integral; it includes not only a person’s individual context but also the broader socio-political context in which they live and receive health care. Taking a relational autonomy approach (Sherwin) can help nurses address these gaps in the principalist view of autonomy—which remains dominant in health care today—by exploring what it means to be autonomous within one’s own context. While Sherwin has chosen the term “relational,” she is clear that she could just as easily have chosen the words “contextual” or “socially situated.”
Using a feminist perspective of autonomy allows nurses to acknowledge the distinction between autonomy and agency. For example, if a patient makes a decision regarding a treatment option, but because of accessibility this option is not available to them, their agency has been constrained, although their autonomy—the ability to make that decision—has not. The converse may also be true; as Sherwin (1992) explains, when agency and autonomy are conflated, it becomes challenging to notice that what appears to be an autonomous choice is really nothing more than rational agency. An example is the case of a woman making a decision regarding assisted reproductive technology (ART) treatment within a pronatalist society. They are indeed making a rational choice to have a particular procedure, for example, IVF, and this choice fits with the dominant understanding of autonomy; however, as Sherwin clarifies,

> when we limit our analysis to the quality of an individual’s choice under existing conditions, we ignore the significance of oppressive conditions. Minimally, autonomous persons should be able to resist oppression—not just act in compliance with it—and be able to refuse the choices oppression seems to make irresistible. (p. 33)

Taking a relational approach to autonomy allows one to question the concept of self, recognizing that no individual is ever alone, and that selfhood is “an ongoing process, rather than as something static or fixed” (Sherwin, 1992, p. 35). Using this approach enables attending to the complexity of relationships, the social context of peoples’ lives, and the historical and political factors that influence the decision-making processes. Using a relational understanding of autonomy requires that nurses question the structures and power that can enable or create barriers for a person to fully enact their autonomy. Once nurses can recognize and examine these structural enablers and barriers, they can then begin to engage in actions such as advocacy, research, and education to work towards structural change. This recognition of both structure and power is another significant deviation from the principalist approach to autonomy.
Relational autonomy can be applied to any area of nursing practice and with any population; all nursing clients in all nursing contexts have relevant life contexts that are integral to ethical care. In this chapter, we explore a case related to infertility (Ethics in Practice 11-2) to highlight the complexities that can be addressed when nurses use a relational autonomy approach to care.

**ETHICS IN PRACTICE 11-1**

**Prenatal Care for Trans Indigenous Youth in a Rural Context**

Ramona lives in a rural community three hours north of Prince George, British Columbia, and has been seeking birth control since turning 14 years old and becoming sexually active. Ramona self-defines as gender non-binary. In conversations with youth clinic nurses, they have described significant barriers to accessing trans-youth-specific sexual health and contraception education. Living in a small town for their entire life has meant that privacy and confidentiality is often challenging when seeking care as a minor without parental knowledge.

At 17, Ramona becomes pregnant, and based on past experiences of trying to access reproductive care, determines that they will be judged about being young, trans, and pregnant. Ramona decides that carrying the pregnancy to term without relying on supports and prenatal care would feel safer than travelling to another community or urban primary care setting for health care. When Ramona’s parents eventually learn of the pregnancy, Ramona starts to feel more supported and less alone as the birth approaches. However, at 32 weeks, Ramona experiences spotting and signs of early labour and the decision is made to send them to Prince George for a trial of bedrest. The admission is arranged and Ramona’s parents prepare to make the drive to Prince George. However, the family faces significant economic barriers to secure funds for fuel, accommodation, food, and childcare costs for their other children so that they can leave home to be with Ramona until the baby’s birth. There are no funds accessible in the community that the family can access in order to be able to accompany Ramona. They drive Ramona to the urban hospital, stay while Ramona is admitted and then leave for home. Upon Ramona’s admission to the antenatal unit, the nurse undertakes an intake assessment focusing on social and pregnancy history, and starts by asking: “Why are you alone? Where is your support system? How do you plan to manage these weeks of bedrest?”
Having introduced health equity, reproductive justice, and a relational view of autonomy and agency as critical knowledge to inform ethical care for childbearing individuals and their families, we now turn to two cases that illustrate how these concepts and theoretical perspectives can be translated into care for nurses in practice and leadership roles.

Considering the case scenario above, using a reproductive justice lens and considering intersectionality can help nurses determine what barriers in reproductive and birthing care need to be removed for equitable access to be in place. This means looking beyond the individual level—what Ramona can or cannot do—towards creating practices and policies that support optimal birthing and early parenting support for trans youth, who often face gender discrimination and even violence in non-responsive and unsafe systems. Ramona is both young and gender non-binary, and has faced significant barriers to accessing tailored and safe sexual health and contraception education, leading to their pregnancy, which was the outcome Ramona was seeking to avoid when trying to access services at 14 years of age. Being young and trans positions people in ways that being man/woman (binary) gender and older age do not—and these “positionings” have very real and tangible impacts on the right to sexual health and contraception education regardless of age, gender, or other features of a person’s social identity. Nurses are well positioned to uphold reproductive rights by becoming aware of how these intersecting barriers affect access to perinatal care. They can work to shift power imbalances so that interpersonal interactions are ethical, respectful, inclusive, and safe regardless of a person’s social identity.

**REFLECTIVE QUESTIONS**

1. What does using a reproductive justice lens draw attention to in this scenario?
2. How does using a reproductive justice lens help to determine what is ethical care for Ramona?
3. What should become the focus for action for nursing leaders in this scenario?
Multiple considerations about Ramona’s social context and identity are important as we consider this case. These include that they live in a rural community and the potential need to leave home and be away from family can be stressful when admission to an urban hospital is required. Past experiences of barriers to care have been a reality, and Ramona has not been able to access sexual health education for fear of judgment. All of these experiences compound one another and are relevant for providing ethical care. Using an intersectional view can help nurses see that non-binary peoples may have negative, discriminatory experiences and face social judgment when accessing care. Understanding Ramona’s past experiences of feeling judged by HCPs and not being able to access care can help nurses support their relationship. For example, if Ramona’s baby is born preterm and requires NICU admission, approaching them using preferred pronouns, and inquiring about family support and economic needs while away from home (e.g., meals, accommodation) would reflect an understanding of their context.

In nursing care of childbearing families, there has been a historical tendency to overlook the diverse experiences of women-identifying individuals, particularly when these experiences
intersect with discrimination on the basis of ability, age, sexual orientation, race, and socio-economic status. To illustrate, Indigenous women’s birthing experiences and inequitable outcomes confirm how historical and ongoing colonial oppression and racism, gendered violence, and intergenerational trauma impact perinatal health outcomes and Indigenous women’s experiences of safe and respectful care within clinical settings (Brown et al., 2011; Sheppard et al. 2017; Varcoe et al., 2013). Indigenous women in Canada experience higher rates of preterm birth, low birth weight, and postnatal depression, among other maternal-infant health outcomes. These outcomes are indicative of how interlocking systems of oppression impact childbearing individuals and their families and communities (Sheppard et al.).

Using a reproductive justice framework offers ways to understand how reproductive health disparities, birthing outcomes, and maternal mortality are created through historical and ongoing colonial trauma. There are barriers to the SDOH that current reproductive policies do not address. Reproductive justice has applications for broad, diverse communities that could guide advanced practice nurses to better support racialized women in their reproductive years.

**Accessible Reproductive Care**

We now turn to another Ethics in Practice case to further consider how nurses in both practice and leadership roles can work towards equitable access to reproductive care. In particular, we will discuss assisted reproductive technologies (ART) by integrating a relational view of autonomy and agency.

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**ETHICS IN PRACTICE 11-2**

**Equitable Access to Assisted Reproductive Technologies**

Kaelen and Jade, a same-sex couple, have decided they would like to pursue having a child together, and have started exploring their options. Along the way, they encounter a few challenges and discover that the donor sperm process is more complex than they
had anticipated. Living in a rural area of northern Ontario, they are accustomed to travelling to receive health care, so they aren’t surprised to learn they will have to drive to access a fertility centre. What does come as a surprise is the distance they will need to go, as their more local health care options do not include fertility care. They find themselves driving five hours to the fertility clinic. Once they are patients of the clinic and have had a consultation, they decide that Jade will try to conceive first. Ready to begin their journey as parents, they are disheartened to learn that while fertility care is covered by the provincial medical plan (OHIP), fertility treatment is funded separately through the Ontario Fertility Program. Moreover, this program only covers specific fees for an insemination cycle, not all the fees incurred, leaving them to fund both the cost of each donor sperm sample and the fee required to prepare the sperm for insemination. This will mean that each month they want to try to conceive will cost them almost $1,500. They are also advised that in order to increase the accuracy of the timing for the procedure, and thus their chances of conceiving, they should be monitored at the clinic with bloodwork and ultrasounds throughout their cycle, sometimes every day or two. Jade and Kaelen are at a loss as to how this could work for them, given the distance they are travelling and the time they would need to take away from work. Jade is a teacher, so while she knows she has some protected paid sick days, they will quickly run out depending on how long the process takes. Kaelen, though, works on a contract with the local college, and they don’t have paid sick time. Also, given the contractual nature of their work, they worry that time away might jeopardize the next contract. Therefore, Jade will have to travel down to the city alone for the insemination process.

* Fertility care refers to the physician consult, appointments, and investigations such as ultrasounds and bloodwork used to assess fertility. Fertility treatment refers to the various assisted reproductive technologies (ARTs) used, for example, IVF and insemination.

Fertility care is most often offered in specialty clinics where access to a full suite of ARTs is available, from minimally invasive through to IVF. In Canada, there are 36 clinics that offer IVF, and in 2020, over 30,000 treatment cycles were undertaken (Canadian Assisted Reproductive Technologies Registry [CARTR] Plus, 2021). These clinics are situated mostly in large urban centres in their respective provinces, but in the case of the Maritimes, only Nova Scotia has a full-service IVF centre. Geographic distance alone can present a significant barrier to accessing ART. For instance, in British Columbia, no services currently exist outside the Lower Mainland (although at the time of writing two new clinics were announced, one in the Interior and one on Vancouver Island). In
Ontario, no clinics exist in the north to offer fertility services; all full-service clinics are further south in the Greater Toronto Area (GTA). Considering the Canadian context, where provinces and territories are large and populations are widely dispersed, significant geographical challenges arise for people seeking fertility care. But perhaps even more pervasive are the financial barriers to accessing fertility treatment. Health care delivery and decisions regarding health care spending are done at the provincial level, and so disparity is noted among the provinces. While all provinces fund fertility investigations through the provincial health insurance, at the time of writing, only three provinces provided funding for IVF, two of which were just announced in 2021 (Larsen, 2022). Funding for procedures such as intrauterine insemination, which Jade and Kaelen are seeking, is funded differently across the provinces, and currently none cover the cost of the lab services, such as sperm washing required for the procedure, and none cover the cost of donor sperm.

If we then look beyond the direct financial cost, the added financial burden of fertility treatment becomes evident. Jade and Kaelen have a day’s drive to reach the clinic; this requires time away from work, a working vehicle, gas, and food. If treatment is needed early in the morning, as many clinics require, then there may be the additional cost of staying overnight near the clinic, or the physical cost and risk of travelling through the night. This can create a significant barrier for those who are working in positions with little flexibility or no sick time. Those with precarious work are at risk of having to choose working over their fertility treatment, and so their goal of having a child may be impossible. Jade has the advantage of some paid time off that she could use, but she rightly is anxious about how long that time will last, given what she knows can be a lengthy treatment process.

As part of the LGTQ2S+ community, Jade and Kaelen may face additional barriers, such as questions about their choice to be parents, or feeling out of place in the fertility centre, where much of the care is geared towards treating infertility versus supporting the fertility of those who require donor gametes. Requiring donor gametes also means their financial burden is greater than it is for those who have all the required gametes within their relationships.
The emotional burden of fertility treatment is also significant (Domar, 2017; Greil et al., 2010).

ETHICS IN PRACTICE 11-2 (CONTINUED)

**Equitable Access to Assisted Reproductive Technologies**

Jade and Kaelen go through multiple rounds of donor insemination without success, each one becoming more difficult for them. They begin to wonder if they should proceed with more aggressive treatment such as IVF, or whether perhaps Kaelen should try to conceive and carry. It is a difficult decision, and they struggle to find the right support to aid them in the decision making. They worry about the cost, the process of IVF, and the time away from home and work. In the end, they decide they will wait for Jade to have the summer off from teaching and then try again. They don't want to give up their desire and goal of being parents, but they believe they need time away from treatment, both emotionally and financially. They ask the nurse at the fertility clinic what they should do.

Jade and Kaelen decide that Kaelen will try to conceive. They are successful on their second round of donor insemination and are elated, until at their 8-week dating ultrasound they discover that the pregnancy is not viable; there is no fetal heartbeat, and the pregnancy is measuring small for gestational age. They are given a few options; first, wait for a spontaneous miscarriage, which could take a few days to a few weeks. Second, wait for a surgical procedure (a dilation and curettage [D&C]) to manage the loss. However, with current surgical wait times being lengthy and unpredictable, they are told it may be one to two weeks, and that they would need to be “on call” to come to the hospital. Third, they are told they could use a medication to induce the miscarriage, which is more challenging given their geographic distance from the hospital. Alternatively, they could pick up the medication at their own pharmacy and take it at home, resulting in a miscarriage occurring within 24–48 hours. They decide to proceed with the third option and leave the clinic with a prescription for Mifegymiso, a medication that will induce miscarriage. When they present to their local pharmacy to pick up the medication, they are told that the pharmacist “won't participate in abortions” and so doesn't stock the medication and will not order it in. The pharmacy technician does offer to forward their prescription to another pharmacy. Kaelen calls the fertility clinic nurse in tears to share their experience.

For nurses supporting people, couples, and families through infertility and fertility treatments, a relational approach offers a contextual, comprehensive, and nuanced understanding of the ability of childbearing individuals to enact autonomy and agency. This
would include an appreciation of the potential for the following complexities to impact autonomy and agency: (a) consideration of the social context of women’s experience of infertility, and the stigma associated with infertility in a largely pronatalist society (Nouman & Zanbar, 2020; Sandelowski, 1990, 1991; Sherwin, 1992, 2018; van Balen & Inhorn, 2002; Worthington et al., 2019); (b) a woman’s personal historical context such as her pregnancy history or history of attempted and successful or failed ART treatments to date (Zeiler, 2004); (c) a woman’s familial and community contexts and the importance of motherhood within those relationships (Inhorn, 1996; Öztürk et al., 2021); (d) the ability to refuse treatment when infertility is constructed as an illness or disease (Kalbian, 2005; McQuillan et al., 2022); and (e) a critical perspective on the medical approach to informed consent, which requires “adequate information” and most often only includes medical risks. Donchin (2001) describes the lack of information typically given regarding the emotional, psychological, social—and, we would add, existential risks—associated with treatment. Nurses should also pay attention to the power differentials at work within such a highly specialized and technological context (Kalbian; McLeod, 2017).

When considering the challenges that Jade and Kaelen face as they navigate their fertility journey, it is apparent that the biomedical view of autonomy is insufficient.

Comprehensive reproductive care includes not only care of those seeking assistance with either contraception or fertility and pregnancy, but also management of early pregnancy, including miscarriage and ectopic pregnancy, as well as access to abortion care. With the recent reversal of Roe v. Wade in the United States (Savage, 2022), there is a spotlight on the various situations that could put women and those with a uterus at risk if they cannot safely access services. While abortion, medical or surgical, has been decriminalized in Canada since the 1980s, and covered just as any other medical procedure by provincial health insurance programs, recent events in the US about abortion laws have contributed to reigniting the conversation about abortion in Canada (BBC News, 2022).

Given that Jade and Kaelen’s experience is not uncommon, there is a need for nurses to explore how more equitable, accessible, comprehensive, and compassionate reproductive care can be realized.
Nurses providing care to women and people with a uterus must be aware of and prepared to have conversations about the spectrum of reproductive care. Nurses have a long history of being advocates for women’s health and reproductive choice (Haney, 2021). Unfortunately, the role of nurses to advocate for safe, equitable access to abortion care and reproductive choice is still greatly needed today (National Nurses United, 2022).

**Implications for Ethical Practice for Nurses and Nurse Leaders**

When nurses and nurse leaders use a health equity and reproductive justice approach in providing ethical care to childbearing individuals, it provides them with the knowledge about how to contribute to optimal reproductive, pregnancy, birthing, and neonatal outcomes by supporting autonomy, agency, and access to care. Core strategies for all nurses in perinatal, neonatal, and reproductive care settings include (a) asking questions about peoples’ histories, experiences accessing care, and how to support their agency and autonomy while challenging dominant social norms related to childbearing; (b) using gender-inclusive language; and (c) creating respectful, responsive, and safe care. Taking a relational approach allows for an exploration and understanding of complex structures, power, and contexts that patients bring with them, and impacts how they navigate health, reproductive, and neonatal care. This relational understanding can assist nurses, not only to better prepare for and provide care to their clients and their pregnancies and newborns, but also to enact their role as advocates to work towards recognizing and addressing barriers that restrict autonomy and agency.

Nurses have longstanding commitments to equity and social justice. Realizing both as a means and an end in everyday nursing practice requires critical analysis of structural barriers to care and the social determinants of health, as well as action to dismantle multiple intersecting sources of oppression that occur across the continuum of reproductive care. Nurses who are gender-inclusive and anti-racist can be better positioned to see how ability, class, and age also shape the experiences of childbearing individuals and outcomes of
reproductive, perinatal, and neonatal care. Nurses in leadership roles are exceptionally well-positioned to advance a reproductive health equity agenda within policy, practice, and education contexts. In so doing, they can transform organizations and social structures to create environments and systems where childbearing individuals can navigate their reproductive decision making, pregnancy, and birthing experiences with safety and dignity.

**QUESTIONS FOR REFLECTION**

1. *Some provinces fund IVF for infertile women of childbearing age. Should other provinces follow this lead and fund IVF? Why or why not?*

2. *Given your role as an advanced practice nurse, how might you use a relational approach when caring for pregnant individuals and their families?*

3. *Think about your own practice context. How could you be involved in ensuring that families with limited resources are able to access the continuum of reproductive care?*
Endnotes

1 Structural barriers refer to the broad structures and systems in our society, including (a) institutions and policies, which shape life opportunities; (b) access to resources; and (c) how we are positioned in the social fabric of our society.

2 This clearly distinguishes Sherwin’s use of the term “relational” from those of others who use the term to refer more to interpersonal relationships.

3 Infertility is broadly defined as the inability to conceive, or the inability to carry a pregnancy to term after 12 months of trying. In Canada, it is estimated that one in six couples will experience infertility (CFAS, 2022). Infertility is defined as a “disease” with a variety of causes, some of which can be addressed medically or surgically, and some of which require fertility treatments to circumvent the underlying cause. The host of treatments available are referred to as assisted reproductive technologies (ARTs), the most costly and invasive of which is in-vitro fertilization (IVF). Individuals may also seek fertility care, as shown in Ethics in Practice 11-2 in this chapter, when requiring access to third party reproductive care (for example, donor sperm, donor eggs, or a gestational carrier).

4 Funding models vary by province. PEI and New Brunswick (NB) require the recipient to pay out of pocket up front and will reimburse them after the treatment has performed to a lifetime maximum of $5,000 in NB and up to $10,000 in PEI dependent on income. Of note, Manitoba and Nova Scotia offer a tax credit for fertility treatment costs. Only Ontario and Quebec offer funding structures that reimburse the clinic so the recipient does not have to pay out of pocket up front. This funding comes with restrictions and limits; for example, in Ontario, only one IVF cycle per person is funded; likewise with the funding in PEI. Quebec has a unique history with funding, as it was for some time the only province to offer funding, and offered unlimited cycles to those under age 42. With a shift in governments, that funding was stopped as part of austerity measures. The Quebec government has now reintroduced funding with a limit of three cycles per person.

5 The ability to act as an autonomous agent can be diminished in the face of repeated trauma. Multiple failed ART cycles can lead to such situations for women (Zeiler, 2004).

References


IN THIS CHAPTER, I EXAMINE one of the most vexing questions in children’s health care: What ethical significance should be accorded to the voices of children in decisions about their health care? I argue that we should attend genuinely to the moral voices of children, while recognizing limits to the degree of responsibility that can be assigned to their actions. I argue that this can be managed by interpreting the current standard of child assent more broadly. Specifically, I will (a) highlight the limitations of the prevalent adult-centred modes of construing the experiences of children; (b)
outline a child-centred conception of moral agency; and (c) discuss some of the corresponding implications for advanced practice nurse leaders in children’s nursing.

In the seven Ethics in Practice cases presented below, drawn from my clinical experience, I introduce important themes to orient the discussion throughout the remainder of the chapter. Using these cases, I analyze a range of encounters lived by children that are commonly under-recognized as moral experiences and highlight implications for advanced practice nurse leaders. Such stories are frequently interpreted within adult-centred psychological frameworks that minimize the moral experiences of children as expressions of immaturity. Finally, at the end of the chapter, I will revisit each of these episodes and discuss how they could be navigated with improved sensitivity to the moral agency of children. Following the cases, I will describe the dominant practice standards that are used to examine ethical concerns in clinical care with children.

Narratives of Moral Experience

**ETHICS IN PRACTICE 12-1**

*Coercive Moral Language*

William is a five-and-a-half-year-old boy who has come in for day treatment requiring the administration of an intravenous antibiotic. His parents have indicated that William has been dreading coming to the hospital; his fears centre on the needle and the injection process. He has shed a lot of tears in the couple of days leading up to his treatment. As the nurse gently approaches William to start the intravenous, he becomes pale and silent. He readily cooperates with every instruction that the nurse gives him: holding out his arm, making a fist, and taking a deep breath as the needle is inserted. Each time William cooperates with an instruction, the nurse warmly tells him, “Good boy, William. You’re such a good boy. What a big boy you are.”
ETHICS IN PRACTICE 12-2

Unspoken Diagnosis

Benjamin is a twelve-and-a-half-year-old boy with a metastasized, inoperable abdominal tumor. Benjamin's parents have been asking for help because he has been frequently crying at home; he is discouraged about all the time he has to spend at the hospital and misses his friends so much. His parents have also indicated that they do not want Benjamin to know his diagnosis, because that would discourage him further. They have been telling Benjamin that the intravenous chemotherapy he receives is antibiotics to fight an infection.

ETHICS IN PRACTICE 12-3

Anticipating Suffering

Gloria is a six-year-old girl with a degenerative neuromuscular disorder. She has been admitted to the hospital with respiratory failure that has been judged to be an end-stage manifestation of her neuromuscular disorder. She will require long-term mechanical ventilation. Gloria’s parents, who have always been by Gloria’s side providing her with exceptional care and love, are devastated that she will never be able to breathe on her own again. They have decided to terminate Gloria’s life support, to let Gloria die, believing this to be preferable to the long life of suffering they foresee for her. Meanwhile, most of Gloria's health care providers (HCPs) see Gloria as a playful girl who loves her hobbies, including loud music and celebrities. They have frequently observed Gloria laughing out loud as she watches videos with her parents or her favourite nurses. Gloria seems to enjoy her life.
**ETHICS IN PRACTICE 12-4**

*Protective Secrets*

Nine-year-old Marianne has been in the intensive care unit for two days for the care of severe injuries following a major car accident. This accident took her father’s life. Following two days of unconsciousness, Marianne is awakening rapidly despite her ongoing need for support of vital functions (such as mechanical ventilation). Clearly agitated, she is mouthing questions about the accident and asking for her father. Her mother and the HCPs caring for her are torn over whether it is better to tell Marianne the truth about her father’s death immediately or to invent a less painful account to tell her for now, with the intent of telling her the truth at a later time.

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**ETHICS IN PRACTICE 12-5**

*Hurt in the Crossfire*

David is an eight-year-old boy who frequently comes to hospital for the management of recurrent back pain. Over the past year, he has become increasingly involved in identifying ways to manage his pain. Despite this, the frequency and intensity of his pain have increased significantly in recent months. One day David discloses that he is very upset over how much his divorced parents fight over him. He says that “They’re so busy fighting all the time that they don’t think about how it hurts me so much to see my mom and dad arguing over me. Sometimes I wish I wasn’t there so they wouldn’t have to fight so much. What good am I? Some days I wish that they would just play with me or just think about me.”

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**ETHICS IN PRACTICE 12-6**

*Struggling to Escape*

Robbie is a fourteen-year-old boy who has survived a four-week stay in an intensive care unit. He received treatment for severe burns he sustained in an apparent accident while manipulating a stove. Robbie has just been taken off the ventilator with his endotracheal tube removed so that he can once again use his voice. During a particularly intense conversation talking about the painful ordeal he has just been through, Robbie says that the incident with the stove was not an accident. He says that he tried to kill himself and wanted to die because he could no longer bear to see his father physically abuse his mother every evening after his father got drunk.
Examining the Conventional Framework

The clinical care of children often raises complex ethical issues, as illustrated in the case narratives above. One of the most challenging (and least resolved) of these issues concerns the extent and type of involvement that children should have in decisions regarding their health care. As with adults, in health care, informed consent is required for the treatment of children. If a person has the mental capacity to do so, consent must be provided, and must be based on the provision of all relevant information. Consent must also be free of any undue influence or coercion. Some Canadian provinces and territories have legislated a specific age of consent for health care treatment, below which a minor cannot autonomously provide legally valid consent. For example, in Quebec, minors have the right to provide consent for treatment required by their state of health—with some limitations—at 14 years of age. In many other jurisdictions throughout Canada and the United States, no specific age threshold is legislated. The child’s capacity should be assessed on a case-by-case basis, although it is largely agreed in practice that this capacity should be recognized at about 14 years in general. This leeway allows for the assessment of children younger than 14 on the basis of their demonstrated capacities.

ETHICS IN PRACTICE 12-7

Please Don’t Tell My Parents

Cam (a gender-neutral pseudonym) is 11 years old. They have come to a community clinic with their parents. The parents brought Cam to the clinic because they think Cam is feeling depressed. Following an initial consultation with the family, the interdisciplinary team asks the parents to leave the room so they can speak with Cam alone. The parents agree to leave. Cam reports that their parents are angry because Cam does not want to wear boys’ clothing. Cam discloses that although they were raised as a boy, they feel more like a girl. Cam seems relieved to talk about these feelings. They are not seeking any particular intervention for now, but plead with the clinic’s team not to tell their parents because they “would not understand” and “would be very angry.”
The Canadian Pediatric Society (CPS) has published seminal statements regarding health care treatment decisions involving children (Coughlin, 2018; Canadian Pediatric Society, 2004). These statements reflect the legal and ethical norms that are widely agreed upon throughout Canada and the United States (Katz et al., 2016). The CPS states:

Capacity is not age- or disease-related, nor does it depend on the decision itself, but is a cognitive and emotional process of decision making relative to the medical decision. … Children who have partial skills to make decisions should be recognized as having some authority over their own health care. … Children and adolescents should be appropriately involved in decisions affecting them. Once they have sufficient decision-making capacity, they should become the principal decision maker for themselves. (CPS 2004, pp. 100–101)

The CPS highlights that some pre-adolescent children, particularly those with more experience with illness, may have greater capacities to make health care decisions than other children their age (like eight-year-old David’s pain management in Ethics in Practice 12-5). Alderson et al. (2006) have demonstrated that children with juvenile (Type 1) diabetes who had decision-making experience in the past were subsequently more capable of making other decisions regarding their health care. Age was not found to be a distinguishing factor in the determination of capacity. McPherson (2007), in her examination of children’s participation in chronic illness decision making, challenged the prevalent view of decision making as a discrete, autonomous, decontextualized process. McPherson uncovered the contextual basis of children’s participation; relational processes indistinguishable from everyday decisions, embedded in children’s relationships with parents, teachers, friends, and HCPs. Children’s participation involved two domains: first, the resonance of children’s voices (i.e., opportunities and abilities to formulate and express their views), and second, the relevance of children’s voices (i.e., the standing children achieved within decisional processes).
In short, these researchers suggested that children’s decisional capacities vary widely. Prior decision-making experience can significantly enhance a child’s capacities. Thus, individualized assessment of a child’s participation in decision making is important, both in terms of properly recognizing the child’s current capacity, and in promoting the child’s ongoing capacity development.

Although there is some recognition of children’s capacity to consent by organizations like the CPS, the prevalent bioethical and legal framework for health care decisions involving children usually reflects the best-interests standard (Coughlin, 2018; CPS, 2004; Katz et al., 2016; Miller, 2010). This standard requires legally authorized, surrogate decision makers to weigh the burdens and benefits associated with each treatment option. However, many cases present complex scenarios in which the benefits and burdens are difficult to judge, as they relate to goods that cannot be ranked according to any universally agreed upon criteria. For example, in Ethics in Practice 12-3, Gloria’s parents and HCPs do not agree on whether the burdens in her life render it unworthy of ongoing support.

Furthermore, how can the significance of quality of life be ranked in relation to the sanctity of life as a good in itself? Some members of diverse ethnocultural or religious communities argue that the preservation of human life is mandatory, regardless of the quality of that life. Others argue that life is only valuable in terms of the quality of life that can be achieved (Carnevale, 2005a). Disagreements between parents and HCPs regarding a child’s best interests—and which benefits and burdens should be attributed greater weight—may inadvertently perpetrate social injustices. Some forms of living may be tacitly valued and considered worthy of support (for example, people who are able-bodied or those with unaltered mental functions), while other forms of living are considered “futile,” warranting withdrawal of life-sustaining interventions (for example, people with some form of disability) (Carnevale et al., 2006).

In light of the difficulties inherent in reconciling such ethical problems, the most widely accepted view is to recognize parents as the surrogate decision makers for minors (Coughlin, 2018; CPS, 2004; Katz et al., 2016; Miller, 2010). This can be traced to the modern Western value assigned to the autonomy of families. It is
largely held that families should be enabled to establish their own respective moral norms because such judgments should be based on the loving intimacy that is commonly inherent in familial relationships (Nelson and Nelson, 1995).7

It is also recognized that the cultural and religious freedom of families should be respected (Canadian Charter of Rights and Freedoms, 1982). Here, too, the state imposes some limitations in situations where such freedoms conflict with more fundamental rights. For example, in cases where a minor has a life-threatening condition that can be effectively corrected with a blood transfusion, the courts have commonly overruled the objection to such transfusions by Jehovah’s Witnesses, declaring that a child’s right to have their life preserved overrides their family’s religious freedom.8 However, while substantial strides have been made in the arena of children’s rights by rulings like this and by organizations like the CPS, there is still much work to be done.

### From Moral Object to Moral Subject

Throughout this chapter, I argue that children should be regarded as moral subjects—agents who are highly capable of moral awareness and understanding. However, several researchers have demonstrated that children are frequently exploited, not as moral subjects, but moral objects. In other words, children are regarded as a means to the moral pursuits of the more powerful adults in their lives (Carnevale et al., 2021; Greene and Hogan, 2005). As a result, a child’s right to informed consent regarding their own health care is frequently subjugated.

 Recognizing such rights for children is a fairly modern concept. The moral worthiness of the lives of individual children has not consistently been a universally held value. In his analysis of this topic in England at the turn of the twentieth century, Wright (1988) argued that a drop in infant mortality due to advancements in medicine corresponded with a period of urbanization and diminution of family size, increasing each child’s worth as a future source of labour and revenue. In effect, while the worth of children’s lives increased, that worth still pivoted on their economic value rather than their inherent moral value. The moral objectification of
Children were construed socially as both material possessions and as “selfish” burdens on their surrounding adults.

While the language and motivations may have changed, the moral objectification of children continues to be found in contemporary clinical encounters. Parents commonly speak of the enormous burden they feel to do right by their children and ensure that they get the care they deserve (Carnevale et al., 2006; Carnevale et al., 2007). Parents are often overwhelmed by their sense of duty about being a good parent. They also struggle with profound apprehensions about the possibility that their child may die. Although parents are often the most suitable advocates for their child, the child’s interests are intertwined—and sometimes even conflated—with the parents’ own interests.

Similarly, conscientious HCPs may be authentically concerned about a child-patient’s interests. However, these interests are sometimes difficult to distinguish from an HCP’s own interests in attending to other patients. Furthermore, having a reasonable quality of work-life while pursuing opportunities for clinical innovation may be beneficial for the child, and yield professional recognition for HCPs. Health care institutions (e.g., hospitals), too, may be motivated to ensure that patients get the care they require while also balancing that care with the hospital’s own interests in containing costs or pursuing politically meaningful goals. Thus, although an ill child may be surrounded by various adults claiming to advocate for the child’s best interests, these adults are also pursuing their own interests. Given the significant power imbalance between these adult agents and the largely silent, morally subordinated children, the latter run a significant risk of moral objectification. This objectification can further perpetuate the social injustices experienced by children, as the interests of adults can prevail over those of significantly disadvantaged children.9

What About the Voice of the Child?

As HCPs use the best-interests standard to assess ethical concerns related to children, they may cast children in a highly passive role,
depending on how this standard is applied. Children’s voices are commonly muted. I attribute this problem to two phenomena: first, underestimation of the “maturity” of children’s moral reasoning, and second, the “adult-centredness” of how the best-interests standard is commonly used. I will discuss these topics separately in the following two sections.

**Recognizing the “Maturity” of Moral Reasoning in Children**

Children (or legal minors) are more capable of engaging in what is regarded as “mature” moral reasoning than is typically recognized. In a 1990 brief submitted by the American Psychological Association (APA) in the *Hodgson v. Minnesota* case, the APA stated: “[By] age 14 most adolescents have developed adult-like intellectual and social capacities including specific abilities outlined in the law as necessary for understanding treatment alternatives, considering risks and benefits, and legally competent consent” (Schneider et al., 1989, pp. 8–20, cited in Melton, 1999).

No universally accepted standard exists for determining when a child’s voice is to be regarded as a sufficiently capable expression of an autonomous will. Children’s voices matter, but when and how they matter is determined by a case-by-case interpretation of the child’s decisional capacities. This may imply that six-year-old Gloria in Ethics in Practice 12-3 may not be considered to have adequately developed capacities to be attributed significant ethical and legal weight regarding her life-support treatment preferences. Similarly, this view could be extended to Benjamin’s parents withholding a grave prognosis in Ethics in Practice 12-2, on the basis of their belief that he would be unable to process such news.

**Confronting the Adult-Centredness of the Best-Interests Model**

The best-interests standard is commonly imagined and operationalized within an adult-centred conception of moral agency (Carnevale et al., 2021). This conception corresponds with the doctrine of self-determination underlying ethical decision making in adults. Adults are regarded as self-determining agents capable of independently judging their respective moral interests. Fur-
thermore, it is understood that persons should not be impeded in their pursuit of these interests.11

This ideal of autonomy is further expressed through the use of the leading psychological frameworks where moral development plays a key role (Erikson, 1950; Levinson, 1978). In these frameworks, a moral norm for mature adults as highly rational and autonomous is articulated. Children are consequently regarded as less mature—or immature—and therefore as not worthy of comparable recognition as moral agents.12 Consequently, these immature agents, construed as incapable of rationally discerning their own moral interests, are classed as moral minors who are dependent upon adult custodians for the care of their interests. However, the cases of David, Robbie, and Cam in Ethics in Practice 12-5, 12-6, and 12-7, wherein the young people are concealing their principal concerns or diminished sense of self-worth, demonstrate how adult custodians can be highly misinformed or mistaken in their understanding of children's moral lives.

Piaget (1932/1965), a pioneer in the formulation of such psychological frameworks, characterized moral development in terms of three stages: constraint, cooperation, and generosity. Kohlberg (1981) drew on this Piagetian model to develop his own three-level framework for moral judgment in adolescents and adults: preconventional, conventional, and postconventional levels. An individual at the preconventional level is self-centred; the individual formulates moral norms in terms of their own needs and is essentially incapable of construing socially shared views. In conventional morality (associated with the preadolescence-adolescence juncture), the “good” or “right” thing to do is contextualized by social values and moral norms that sustain relationships, communities, and societies. The postconventional level involves a reflective view that transcends the conventional, seeking to discover—through a process of personal enlightenment—a universal construal of morality.

Kohlberg's framework is differentiated along a six-stage (three-level) model of moral development. The child is characterized by Kohlberg as starting at an egocentric and individualistic view of rightness based on avoidance of punishment and individual need (stages one and two). From there, they progress to an under-
standing based on “The Golden Rule” (that is, putting oneself in the shoes of the other person) and shared conventions of societal agreement (stages three and four). Finally, the child develops a principled understanding of morality that upholds the basic rights and values of society and a free-standing logic of universal principles that all humanity should follow (stages five and six) (Kohlberg, 1981). For Kohlberg, the ultimate morally mature person is capable of drawing on a highly deductive logic and engaging in rational reasoning to arrive at an ethically principled conception of justice.

The conceptual soundness of these leading theories of moral development has been challenged by Gilligan in her book *In a Different Voice: Psychological Theory and Women’s Development* (1982) when describing her study of moral experience among girls and women. She has argued that the Piaget and Kohlberg models are based on studies of boys and men and consequently give rise to a male-centred conception of moral development.13 While Piaget and Kohlberg have argued that humans (i.e., men) strive to become *independent* moral agents, Gilligan reported that girls and women strive to be *interdependent*. Girls and women, Gilligan argued, speak of moral matters in a different voice.

Gilligan’s moral orientation toward care and responsibility distinguishes the moral agency of women from the moral agency of men. According to Gilligan (1982), men are primarily concerned about justice and the preservation of the rights of individuals, with an entitlement to freedom from interference in their pursuit of self-fulfillment. Proponents of this feminist challenge to the conventional, male-centred view of morality have suggested that women may employ a different moral framework than men, raising the plausibility that additional distinctive moral frameworks can exist. In the next section, I argue that although children may not reason according to the prevailing adult, male-centred Kohlbergian morality, nor the female-oriented framework advanced by Gilligan, there exists a significant body of evidence indicating that children are capable of a rich degree of moral awareness. The moral viewpoints of children should not be judged in terms of how they might resemble or approximate adult moral reasoning, but instead warrant recognition on their own merits.
The Moral Awareness of Children

Numerous authors have highlighted that children have a greater awareness of morally significant matters than is commonly granted. Yalom (1980) asserted that children’s first awareness of death can emerge as early as three years of age. Bluebond-Langner (1978) published a seminal ethnographic study of three- to nine-year-old children’s encounters with leukemia. She revealed the silent experiences of children’s struggles with sickness and dying, demonstrating a depth and richness in the children’s comprehension that far surpassed the understandings attributed to them by the adults in their lives. Particularly remarkable was how these children willfully complied with social taboos and respected the silence that adults seemed to prefer in relation to the children’s foreseen mortality. These findings correspond with Benjamin’s case in Ethics in Practice 12-2. Children’s silences should be interpreted thoughtfully. Their silence may sometimes demonstrate their motivation to conform to socially desired behavioural norms for children, rather than an incapacity to understand what is happening or moral immaturity.

Sourkes (1995), when discussing the experiences of children with life-threatening illnesses, found a rich depth of awareness in these children’s thoughts about death. Sourkes reported (a) accounts of anticipatory grief among children facing their own deaths; (b) children’s temporal understanding of death, with a comprehension of contributory causes and consequences; and (c) children’s abilities to reflect on matters pertaining to a broad moral order. In the cases of Benjamin and Gloria (Ethics in Practice 12-2 and 12-3), both children seem to have a limited awareness of their situation. This can be partially attributable to restrictions in the information that was available to them. In light of Bluebond-Langner’s (1978) findings, they may have also realized that the adults in their lives prefer that they inhibit expressions of their moral experiences.

Davies (2017) demonstrated how children actively strive to make sense of their world and find ways of being following the death of a sibling. Attig (1996) argued that children are able to anguish existentially and wondered about how they viewed their “finite
existence, the nature and purpose of life, God, punishment, fate, what is fair, and the meanings of suffering and death” (p. 21). In Ethics in Practice 12-5, David described himself as a cause of his parents’ fighting while also expressing moral outrage toward the unfairness of their spending insufficient “quality time” with him.

Coles (1986) examined the moral experiences of children in his acclaimed book *The Moral Life of Children*. He related accounts from poor families in the southern United States to convey that children do not simply express the views of their parents; they are capable of formulating and asserting their own independent sense of how the world should be. He explained that the moral life of children can be characterized as charitable, but also “by extended stretches of moral stinginess, amoral self-absorption, even a persistent immorality that takes the form of spitefulness, rudeness, assaultiveness” (p. 44). Coles argued that children’s actions that are sometimes characterized as immature misbehaviour can at times reveal a greater moral awareness and intentionality than usually considered. Even when children act “badly,” this behaviour can be considered a demonstration of their moral agency.

In my own work with critically ill children and their siblings, I have witnessed rich expressions of children’s moral lives (Carnevale, 1997, 1999a). Bereaved siblings, ranging from five to nineteen years of age, expressed feelings of guilt about the ways they may have acted toward their deceased sibling, demonstrating a capacity for moral contemplation. Many siblings expressed outrage towards the attention accorded to their seriously ill or deceased sibling. Although their parents might have regarded such sentiments as amoral, they nonetheless expressed the child’s sense of right and wrong. David, in Ethics in Practice 12-5, expressed outrage toward his father because he frequently did not follow through on his promises to make time for him: “He thinks only about himself. He’s selfish! I feel like I’m useless to him—just a bother for him.” Here, David condemns what he perceives as morally wrong parenting.

Although their demeanours may sometimes fall short of what adults might consider virtuous, children nonetheless express a moral stance toward their world. Children are morally aware; sometimes with rich complexity, at other times with a simplistic matter-of-factness. Although the moral values children hold may
sometimes correspond with those commonly held by adults, their moral awareness should not be judged according to an adult-centred standard. Given their unique perspectives on the world, it is understandable that children may hold some distinctive moral outlooks. Rather than construing these moral views as immature forms of what is to follow later in their developing lives, according to adult-centred moral development models, the moral views of children merit recognition in their own right. The works outlined above justify a call for the recognition of the moral voice of children—a further “different voice”\(^\text{14}\) (Carnevale et al., 2021; Esser et al., 2016).

**What About Moral Responsibility?**

Some may argue that it is mistaken to speak of moral agency in children without a direct implication of moral responsibility. In this line of reasoning, the moral agency of children should be construed narrowly because of the limited formal responsibility that can be assigned to their actions, given the limited understanding some children may have of the world around them. On the other hand, it could be argued that if health care providers want to broadly acknowledge the moral agency of children, then they ought to assign them a proportional degree of responsibility (Campbell et al., 2011).

This relating of responsibility with moral agency can be traced to Aristotle’s *Nicomachean Ethics* (350 B.C.E./1985).\(^\text{15}\) Aristotle rooted moral responsibility in the voluntariness of human action. He further elaborated two conditions that preclude an act from being voluntary: ignorance or compulsion.\(^\text{16}\) Perhaps some children’s actions could be considered morally involuntary in light of two factors: their variable understandings of the morally significant particulars in their surrounding world and their occasional, apparently compulsive urges to gratify emerging needs. Ignorance and compulsion may both be manifested, for example, in an act of running across a highly dangerous street to chase after a ball.

Following Aristotle’s framework, it can be argued that the degree of moral responsibility that ought to be assigned to children’s actions should vary according to the genuine voluntariness of their actions. Although there may be grounds for limiting their responsibility for the consequences of their actions, this should not
imply a diminution of their moral agency. Considering the depth of moral awareness of which children are capable, they can experience moral distress, guilt, remorse, indignation, and pride—a full range of conscientious sentiments. Therefore, they should be accorded significant recognition as moral agents. That is, children’s voices merit genuine attention—not just a curious listening to the perspective of an immature moral inferior. Children’s voices should not be discounted by adults wanting to accomplish what they consider required, using coercion as they judge necessary, for example, as with William in Ethics in Practice 12-1.

Agency Within a Moral World

I have argued throughout this chapter for a maximization of our attentiveness to the moral voices of children. I should add that attending to the moral lives of children consists of more than solely recognizing their individual moral experiences. In light of their relative position of disempowerment, consideration should also be given to the fragility of their “moral worlds.” Given their limited capacities to shape their own particular worlds, children rely on the significant adults in their lives—who model enactments of “right and wrong” ethical comportment—to help build and sustain their world’s moral order. Moral order refers here to the ways concepts such as right and wrong, good and bad, and just and unjust are defined by the child’s social and cultural context (Carnevale, 2005a). Children also form their own moral outlooks, in the manner outlined in this chapter. They forge modes of coexistence, continually negotiating cooperation with adults in their lives. Cooperation enables children to develop their particular moral character, a character they can then express and cultivate within their adult-dominated moral order.

Some traumatic experiences for children may rupture their moral order, resulting in extreme moral distress (Carnevale, 1998). To gain insight into a child’s moral order, it is useful to consider Robbie, the boy featured in Ethics in Practice 12-6. Robbie expressed that his life felt meaningless because he repeatedly witnessed his father assault his mother. His distress could be traced to the disruption in his moral order. He experienced profound discon-
tinuities in the everyday web of relationships that constituted his social world and moral order. Traumatic experiences like this can disrupt a child’s socially mediated moral order and their ability to rely on adults as sources of comfort and protection against the threats in their everyday lives. While positive experiences can support moral inspiration and the constitution and maintenance of the child’s moral system, negative disruptions in moral order can create extreme distress. In turn, preservation or restoration of positive moral orders can serve as vital sources of comfort.

Therefore, attending meaningfully to the moral lives of children ought to consist of not only authentic listening, but also of genuine consideration toward securing a child’s moral order—their moral world. Within the clinical context, this requires optimizing the stability of relationships that are morally significant for children. In the next section, I discuss how conversations with children to seek their assent for health care can be used as a way to facilitate a child’s expression of their agency.

**Toward a Broad Conception of Assent**

I argue in this chapter that we should attend genuinely to the moral voices of children, while recognizing limits to the degree of responsibility that can be assigned to their actions. The genuine attention I am implying here resembles the “authentic listening” advocated by Rogers (1951) in his client-centred therapy framework, where a clinician seeks a profoundly empathic attunement to the experiential perspective of the patient (Carnevale, 2020). This can be managed by interpreting the current standard of child assent more broadly. Obtaining assent implies seeking a child’s willingness to accept the proposed care based on information that has been provided to them about their health condition, proposed investigations, and interventions. This information must be adapted to their language level and intellectual capabilities to optimize their understanding. The American Academy of Pediatrics (AAP) recommends that for children who cannot consent to care themselves, their parents should be responsible for granting permission while giving great weight to the views expressed by the child. Situations involving older children and adolescents should
also include the assent of the child to the greatest extent possible (Katz et al., 2016).

The foregoing discussion of the moral awareness of children implies that this AAP recommendation ought to be applied with an a priori valuation of the significance of the moral lives of children. What children say should be regarded as morally meaningful, and the adults in their lives (e.g., parents and HCPs) should genuinely seek to reconcile any matters that seem to be causing any moral concern for the child. This would involve attending meaningfully to their questions, possible objections, and even their silences.

Some clinical situations can involve complex phenomena—clearly oriented toward the child’s long-term good—that a child may not seem to grasp fully (e.g., emergency surgery for a four-year-old with appendicitis). Although the responsible adults in such a situation (typically the parents) might authorize surgery despite the child’s objections, such an authorization should follow the adults’ best efforts to foster the child’s understanding and acceptance of such an intervention. In the end, if it is judged by those with a duty of care for a child that some interventions may be considered optimal toward promoting a child’s best interests despite the child’s objections, such a coercive overriding of the child’s moral voice should still be regarded as a form of moral wrong. Although overriding a child’s expressed preferences in such a situation may be considered permissible in terms of their best interests, it should still carry the moral significance of a harm—a consequence that should be prevented and ameliorated as much as possible.\(^\text{19}\) This scenario can be distinguished from the approach used by Benjamin’s parents in Ethics in Practice 12-2. Here, morally significant information that would help Benjamin understand what is happening to his body and enable him to express his own preferences toward his care is withheld by his parents, requiring him to undergo chemotherapy without his consent or his assent. In light of my arguments presented in this chapter where I outline the depth of children’s moral awareness and capacities and, subsequently, the moral harms that can be attributed to neglect of their moral agency, the withholding of morally significant information from Benjamin is difficult to justify.
Implications for Advanced Practice Nurse Leaders

The narratives I presented at the beginning of this chapter highlight a diversity of moral concerns that can be experienced by children in clinical settings. The occurrence of such concerns suggests the potential for children's moral experiences to be under-recognized by adults, including their families and HCPs. Some implications for clinical care can be inferred from this analysis of moral agency. Advanced practice nurse leaders can mobilize their nursing ethics expertise as well as interdisciplinary collaborations to redress these concerns.

First, this discussion calls for an authentic recognition of the moral voices of children. The views and sentiments of children have moral worth and ought to be treated as such. For example, there exists a significant body of evidence justifying the requirement of consent for treatment decisions from young adolescence onward (Coughlin, 2018; CPS, 2004; Katz et al., 2016; Miller, 2010). Second, HCPs should strive to maximally apply the standard of assent, with a genuine stance toward the (spoken and bodily) voices of children. HCPs should regard children's views as worthy in their own right and not just as immature expressions requiring attention and pacification—the latter arising from an adult-centred conception of children's moral agency. In short, children's views should be attributed “due weight” in discussions and decisions that may affect them.20

Working towards the increased recognition of children’s participation in treatment decisions, Kenny et al. (2008) have proposed a framework for the respectful involvement of children in medical decision making. They argue for the participative assessment of (a) what the child wants to know; (b) what the child can understand; (c) the extent of the child’s decision-making capacity; and (d) what the child needs to know to participate adequately. In practice, this involves adapting communication practices to each child's ways of understanding and expression. This is optimized through an empathic attunement with the child—continually striving to understand the child's thinking and sentiments regarding their care.21 This involves using voice elicitation methods that draw on verbal and nonverbal methods (including play- or art-based methods, and
drawing on parents and others who know the child well as communication interlocutors or interpreters). Next, it requires interpretation methods that help discern how the child’s communication expresses their moral agency. The approaches used by advanced practice nurse leaders are very important: they can facilitate or impede the child’s agential expression, directly affecting the ability of HCPS to understand the moral dimensions of their experiences (Carnevale, 2021; Carnevale et al., 2017).

Finally, advanced practice nurses and HCPS should also attend to children’s moral order, which is predominantly constituted and sustained by the web of significant relationships in their social world. This would require (a) identifying the persons who matter (morally) in each child-patient’s life; (b) seeking to understand how these persons matter; and (c) striving to find ways to preserve the continuity of such relationships within the context of clinical care. To illustrate, hospital policymakers should facilitate the presence of significant adults for children (Brinchmann et al., 2002). In addition to serving the psychological needs of these adults, these policies can be crucial in minimizing the traumatization of children. So-called hospital “visiting policies” imply a subordination of the significance of families (Carnevale, 1998, 2005b). When parents tend to their hospitalized children, they are parenting, not “visiting.” Characterizing significant family members as “visitors” marginalizes their importance and justifies limiting their presence through restrictive policies. Given children’s complex interdependencies within their families and how children’s well-being is interrelated with their families’ well-being, clinical practices should involve ongoing family assessment and the promotion of required family supports (Carnevale et al., 2017). Moreover, advanced practice nurse leaders should seek to understand the socio-cultural outlooks of children and their families, and strive to adapt their practices accordingly (Carnevale et al., 2017).

Finally, the care of children requires many complex, overlapping areas of expertise. Their care is therefore optimized when diverse interdisciplinary teams can be adapted to each child’s particular needs, drawing broadly on experts in nursing, medicine, social work, child psychology and psychiatry, child life, childhood education, pastoral care, and clinical ethics, among others, as well as
subspecialists within these disciplines (Carnevale, 2003; Carnevale et al., 2017; CPS, 2004).

**Revisiting the Ethics in Practice Narratives**

I end this chapter by returning to the Ethics in Practice narratives presented at the beginning of the chapter to discuss the corresponding implications for advanced practice nurse leaders. I discuss each situation briefly. An authentic approach to these discussions requires a commitment to examining the particularities of each narrative. The goal is to uncover the specific moral phenomena that are involved and corresponding circumstances at issue within each case.

One of the most profound messages that runs through each of the Ethics in Practice narratives (adapted from experiences within my practice as an advanced practice nurse leader) is that we ought to listen to the moral voices of children in a deeply engaged manner, and not trivialize them. In Ethics in Practice 12-1, for instance, this meant sitting with William to listen to his fears rather than only rewarding the behaviour we wanted. In Ethics in Practice 12-7, it was important to listen attentively to Cam’s call for privacy regarding their gender identity experiences to better understand their concerns and what might be at stake, should their confidentiality be breached (Noiseux et al., 2019). After a private space was provided for in-depth discussion, Cam revealed that they were able to feel more authentically like themselves. This was crucial toward promoting a better self-understanding for Cam as a basis for deciding which actions would optimize their well-being.

For Robbie, in Ethics in Practice 12-6, engagement meant ensuring that Robbie was able to continue to express his psychological as well as his physical pain. In fact, after expressing my dismay over the possibility of losing him in my life—by which I aimed to emphasize his moral significance—Robbie told me that my relationship with him helped him to talk about his pain and lighten the meaningfulness he felt in his life.

The promotion of authentic listening is particularly important for fostering a deepened awareness of the moral lives of children among the significant adults in their world. Parents are often moved
by their children’s expressed wishes, especially when they are articulated with a demonstration of the richness of the child’s moral awareness. In Ethics in Practice 12-3, where six-year-old Gloria’s parents wanted to end her life-support, we were able to engage Gloria in a dialogue through which she was able to explicitly express that she enjoyed many aspects of her life. Although she was frustrated by her dependence on technology, she clearly indicated that it was better to be alive in this manner than to not be alive at all.

In Ethics in Practice 12-5, David demonstrated that he was highly capable of assessing his chronic pain in an ongoing manner and determining which pain-management strategies would be most effective in different circumstances. He was able to make important decisions and assume significant responsibility for his care. However, he was so distraught over his parents’ fighting that he was unable to speak with them about how this aggravated his pain. In Ethics in Practice 12-6, Robbie’s inability to speak about his pain gave rise to suicidal feelings. Children in such situations can benefit from advocacy that facilitates the revealing of their masked sentiments. For example, when I arranged a family conference to help David express his feelings, he said that he felt safe knowing that I would be there as an adult who would ensure that he was heard. David’s parents were very upset after hearing their child’s despair. They promised him that they would do everything they could to stop fighting.

In Ethics in Practice 12-2 and 12-4, the cases of Benjamin and Marianne each involved situations in which some of the adults in the children’s lives were withholding significant information from them. Although keeping such secrets may be intended to protect children from emotional pain, they may in fact distance the children from the significant moral matters at hand. This can impede the children’s ability to understand what is happening, as well as their ability to express how this matters to them. In such situations, I have found that parents themselves appear morally distressed about such secrets. Commonly, parents demonstrate a form of relief once the secret is broken (because they believe, on some level, that it is wrong to not tell the truth). As a result, a deeper intimacy between the parents and the child is fostered. It is also important to recognize that most parents strive to protect their
children from harm, which can give rise to a profound sense of burden when they acquire emotionally painful information about their children’s lives.

The promotion of authentic listening is also important for enhancing advanced practice nurse leaders’ awareness of children’s moral worlds. In caring for children like William, in Ethics in Practice 12-1, this can involve discussing how the use of normative terms such as “good boy” can significantly limit the range of feelings that children will openly express while privately experiencing fear, pain, and distress.

**Conclusion**

Much has been written regarding ethical issues surrounding intervention decisions for children. The authors of this literature have predominantly focused on what adults are called upon to decide on behalf of children, and the normative standards that should be employed for such decisions. In this chapter, I draw attention to the voices of the silent agents who are the objects of these decisions: morally aware young subjects living their own moral experiences. I have highlighted ways in which advanced practice nurse leaders can draw on these richer understandings of children’s experiences to inform their ethical practice in children’s nursing and advocate for stronger and more respectful recognition of children’s voices.

**QUESTIONS FOR REFLECTION**

1. **How does this chapter affect your understanding of the role of parents?**

2. **Identify a situation from your practice where a child’s moral agency was under-recognized.**

3. **How would you approach a child differently after reading this chapter?**

The term “children's nursing” is used here, rather than “pediatric nursing,” to reflect a current shift away from the latter, which has been centred primarily on medical pathologies, to the former, which focuses primarily on the child as an active human agent (Carter et al., 2014).

Portions of these narratives have been modified to preserve the anonymity of the persons involved. For example, all of the names presented are pseudonyms.

These cases involve complex socio-cultural and Indigenous diversities. These dimensions have been excluded from the case description, despite their tremendous significance, to guard against the risk of cultural profiling. Thoughtful examinations of these dimensions would require significantly expanded discussions of each case. For a detailed examination of these dimensions and a “thick” analysis of two clinical cases, see Carnevale (2005a).

This discussion is exclusively limited to the context of decisions regarding clinical care. Children's consent to participate in research also raises a number of challenging questions (Carnevale et al., 2008; Ross, 2006), but these are beyond the scope of this paper.

For a detailed review of how consent standards vary by jurisdiction throughout Canada, see Coughlin (2018).

Although the family is generally viewed as the most suitable unit for creating the moral milieu conducive for fostering the healthy growth of children, it is also recognized that, on occasion, some families can neglect or mistreat children. In such cases, there is some acceptance of state interference in family life.


Children can be considered disadvantaged physically (e.g., they are generally smaller and less physically powerful than adults), psychologically (e.g., they commonly have less relational experience than adults and therefore have limited capacities to judge the trustworthiness of particular relationships), socially (e.g., they are usually economically dependent on adults for support of their basic necessities of life), and legally (e.g., they require an adult interlocutor to have their legal rights recognized). These disadvantages can make children vulnerable and predispose them to maltreatment and other risks.

Decision-making capacity should be judged on the basis of an ability to understand relevant information, think and choose with some degree of independence, and assess the potential for benefit and harm, as well as the achievement of a fairly stable set of values (Miller, 2010). Decisional complexity among adolescents has been further discussed by Coughlin (2018).

This view can be traced to a fundamental ethos of individualism in modern Western societies, wherein each human ought to become an independent or autonomous agent capable of judging morally significant matters through a developed faculty of rational discernment (Carnevale, 1999b).
This highlights a fundamental tension whereby cognitive maturity is presumed as a necessary condition for moral agency. Moral development is linked to the development of general skills of rational reasoning (Kohlberg, 1981; Piaget, 1932/1965). This presumption is valid for an adult-centred conception of moral agency. However, I argue for a recognition of children’s moral agency, regardless of their level of cognitive development, especially in light of the ways in which child development models are sometimes used to discount the moral significance of children’s voices (Carnevale, 2021; Carnevale et al., 2021; Greene and Hogan, 2005).

Kohlberg subsequently put forth a reformulated theory that attempted to address criticisms of his earlier work (Kohlberg et al., 1983). The new theory was regarded as too complex and unclear, such that his earlier publications persisted as his most influential work (Shweder et al., 1987).

Although I am employing the metaphor of voice in this discussion, drawing on Gilligan’s (1982) acclaimed work, “listening” to the moral experiences of children should not be limited to attending solely to their verbal expressions. Children commonly express outrage and protest or comfort and acceptance through various modes of bodily and verbal expression (Carnevale, 1998; Carnevale, 2021). See also Kagan & Lamb (1987) for a discussion of the relation of culture to moral development in children.

For my discussion of moral responsibility, I am deeply indebted to Carl Elliott (1996) for his philosophical analysis of responsibility in mentally ill offenders.

According to Aristotle, the type of ignorance that can make an action involuntary refers to an ignorance of the particular circumstances of an action (e.g., injuring someone in response to a suspected yet false threat constitutes an ignorance-based, involuntary injury). Compulsion refers to an act where the drive resides outside the person. This essentially refers to acts committed out of necessity or duress, wherein many would agree that the individual could not really have done otherwise under those particular circumstances.

This is further related to professional practice with children in Carnevale (2020) and Carnevale et al. (2021).

Assent should be distinguished from consent. Free and informed consent is legally and ethically recognized as a necessary condition for providing care, even with children. If the child does not have the decision-making capacity to provide consent for a specific form of care, then this consent should be provided by the legally-authorized surrogate decision-maker for the child (e.g., a parent). Assent is not legally recognized as a standard for clinical care, although it is a standard within research (e.g., a child’s voluntary cooperation is required to involve them in a non-therapeutic study). I am arguing for the recognition of assent as an ethical standard that can provide a way to recognize children as legitimate participants in discussions and decisions that affect them, when they do not have the legal right to provide consent for themselves.

This acknowledges the importance of retaining some form of the best-interests standard for a preliminary discernment of which treatment options might be best for a child. It also encourages HCPs to continue to recognize the significance of parents as surrogate decision makers because the common intimacy of their relationship predisposes them (more than most other adults) to think in terms of the child’s interests. However, a corresponding recognition of the moral views of children problematizes objections or exclusions they experience toward treatment.
decisions made by their parents. This fosters a greater consideration of the child's voice and also enriches the parents' understanding of the benefits and harms attributed to various treatments by better recognizing that certain courses of action are morally distressing for the child. It is noteworthy that in the context of research, it is widely held that a child's expression of dissent should be respected (Carnevale et al., 2008). “Children can be seriously harmed by having something done to them without their knowledge or understanding” (Baylis et al., 1999, p. 8).


21 I have published a detailed description of how "empathic attunement" can be operationalized in practice and in research, using the concept of "thick voices" (Carnevale, 2020).

References


“High quality home care should be universal, no matter where it is being delivered, who is delivering it or who is receiving it.”
(Canadian Home Care Association, 2018, p. 1)

Many nursing and other health services previously provided in institutional settings are now being offered in the homes of Canadians. The demand for home care services will continue to rise significantly as the Canadian population ages and as older adults hope to live independently in their homes and communities as long as possible (Johnson et al., 2017). Technological advances have allowed for more medical treatments and assistive and monitoring devices to be offered in the home, including “high-tech” interventions that, for example, involve chemotherapy, intravenous
therapy, and dialysis. The COVID-19 pandemic has led to the increased use of telehealth and other forms of virtual consultations in the home environment (McDonald et al., 2021). Home care services are delivered for people of all ages with the goals of helping people to maintain and improve their health; assisting people to remain independent; supporting family caregivers; and helping people to receive treatment, rehabilitation, or palliative care at home (Health Canada, 2016).

As Canadians are currently not entitled to home care services under the Canada Health Act (CHA) (Government of Canada, 1985), each province or territory can decide and design what services it will provide and who will pay for them. The result is tremendous variation among provinces and territories with respect to access and availability of home care services paid for by government (Johnson et al., 2017). No clearly defined basket of government funded services is available to all (Expert Group on Home and Community Care, 2015). Services for Indigenous communities are particularly variable in terms of quality and availability, especially for those living in rural, remote, and northern communities (Johnson et al., 2017).

As a result, many people without adequate resources must rely on family members, when they are available, to provide care in the home that is comprehensive, medically complex, and potentially life sustaining. As the population ages, with many older adults living with chronic conditions, the sustainability of our health system is threatened if more resources are not provided to the home care sector. It is estimated that over one third of Canadians with home care needs are not having these needs met (Gilmour, 2018a), and that one in nine newly admitted long-term care residents could likely have stayed at home with more services (Canadian Institute of Health Information [CIHI], 2020). In addition, there is a small population of children and youth with complex medical needs who require additional care outside of hospitals (Cohen et al., 2018).

In this chapter, we argue that this lack of resources is the result of shifting services to the home, outside of the protection of the CHA. This shift has been made possible by a neoliberal political ideology. We address some of the implications of current home care policy, particularly those that concern the well-being of clients, families,
and home care workers, and those that have an impact on nurse-client-family relationships. We then offer recommendations, where we challenge neoliberal values and beliefs to inform the work of both nurses directly providing care and those in leadership roles. While there are numerous community health nursing roles, including roles for advanced practice nurses (APNs) and other leadership positions in community health, we focus on those in home care in order to provide a rich analysis of the kind of ethical issues that these community nurses might face.

Traditionally, home care nurses have embraced the value of home and family as foundational to practice. They hold a deep commitment to holistic and family-centred care that encompasses health promotion and disease prevention. As guests in the homes of their clients, home care nurses have valued collaborative relationships with clients and have striven to adapt to a never-ending variety of client-controlled environments (Hemberg & Bergdahl, 2020). Home care nurses have had the privilege of coming to know their clients and families as they live their lives. Fiscal restraints, however, have constrained home care nurses’ capacity to provide care holistically. Heavier workloads and clients with increasingly complex medical needs receiving home care have led to the rising use of technology in the home (Ganann et al., 2019). Economics plays an influential role in care provision constraints experienced by nurses and home care case managers.

The Political Context: Neoliberalism

Prior to the CHA, two federal Acts—the Hospital Insurance and Diagnostic Services Act (1957) and the Medical Care Act (1968)—governed hospital and medical care insurance in such a way that all Canadians were entitled to medically necessary hospital and insurance programs. The CHA (1985) replaced these Acts but retained the basic principles underlying the existing national health insurance program and eliminated extra-billing. The CHA contains five well-known requirements that the provinces and territories must meet to qualify for full federal funding, including public administration, comprehensiveness, universality, portability, and accessibility. However, these apply to insured health care services only; that is,
medically necessary hospital services, physician services, and surgical dental services provided in a hospital. They do not apply to extended health care services, such as aspects of long-term residential care and the health aspects of home care (Health Canada, 2016). Consequently, as home care becomes more prevalent, the CHA is increasingly incapable of protecting the health care needs of Canadians. In fact, there are approximately 6.4% of households in Canada receiving home care services, and only 52% of these services are being paid solely by government (Gilmour, 2018b).

During the 1970s, the demand for free market economies and distrust of economic regulation fuelled the rise of neoliberalism, which affected changes in health care structures that left many people without coverage, including those who required home care services (Sparke, 2017). The political and social philosophy of neoliberalism has resulted in an emphasis on the following:

1. The reduction of public/state responsibility for health through the shift of responsibility to individuals and families.
2. The belief that the market is the best allocator of health and social resources.
3. The requirement that individuals take responsibility for their own health and health improvements, including the need for self-care and care for family members during long-term illnesses.
4. The idea that society is composed of competitive and economically focused autonomous individuals.
5. The belief that health promotion is about individually driven behavioural changes as opposed to understanding the social determinants of health (Coburn, 2000; Navarro, 2009; Sparke, 2017).

With markets functioning as resource allocators, the lack of government intervention in the form of social assistance and income redistribution can be justified from a neoliberal perspective. For instance, the neoliberal agenda to restructure home care often includes decentralization: transferring responsibility from the central government to a local or regional level with the aim of reducing administrative costs to meet the needs of local communities.
Yakerson, 2019). The reorganization of service delivery also includes the privatization of services, resulting in the reduction of services under the guise of providing individuals with more choice about which services they need (Yakerson, 2019).

Adherents of neoliberalism promote a view of justice centred on the idea that people receive a fair distribution of goods according to free-market exchanges. Market inequalities are seen as “just” because greater personal wealth is seen as a reflection of the work one has put into serving the needs of the market. Inequality, from this viewpoint, can be justified, because it is presumed that individuals are equally equipped to compete for resources. Public and social expenditures, such as health care, are viewed as a source of inefficiency and waste. Free-market forces and private profits are substituted for the collective public good (Navarro, 2009; Williams et al., 2001).

At the heart of neoliberalism are core ideals that threaten the values fundamental to the CHA, as well as to the ideals of Canadian identity. The ideals of neoliberalism are contrary to the values of home care nurses. One of the core ideals of neoliberalism is the belief that the free market is a just allocator of resources, such that each person fairly receives their share of resources by virtue of market exchanges. In contrast, the CHA is based largely on the belief that justice is served when each person receives their share of health care resources according to need, a central principle of Canadian identity. Many Canadians view Medicare as a source of public pride, not just as a source of insurance, but because it represents “an implicit social contract between governments, health-care providers, and the public—one that demands a shared and ongoing commitment to equity and solidarity” (Martin et al., 2018, p. 1718).

The Community Health Nurses of Canada (CHNC) (2011), through the Canadian Community Health Nursing Standards of Practice, also promotes the advancement of social justice by facilitating universal and equitable access to conditions for health and health services. The CHNC recognizes that socio-political issues may underlie individual and community problems.

Social justice can be viewed as an opposing perspective to market justice (Beauchamp, 1999).
Matters of social justice concern whether the background conditions of people's actions are fair, whether it is fair that whole categories of persons have vastly wider opportunities than others, how among the opportunities that some people have is the ability, through the way institutions operate, to dominate or exploit others, or benefit from their domination and exploitation. (Young, 2011a, p. 38)

Beauchamp argues that unless collective burdens are assumed, the environment, heredity, or social structures will prevent all persons from receiving health protection and a minimum income. Market justice is not appropriate for the distribution of health-related resources because factors such as disability, gender, age, and poverty impede people's abilities to access formal health care services and improve the determinants of their health.

In neoliberalism, there is an emphasis on the self-interested and autonomous individual versus the collective. Such a system does not enable health workers to support communities that have challenges accessing certain health resources. Outside of immediate family and friends, others are viewed as competitors for scarce resources, and are blamed and punished for their problems, rather than helped. This individualistic market orientation elevates the level of social fragmentation, lowers the level of social cohesion and trust, and heightens the sense of relative deprivation in society. It also contributes to income inequalities, higher rates of violence and racism, less community involvement, more chronic anxiety, and a lowered health status of citizens (Coburn, 2000; Wilkinson & Pickett, 2007). This individualistic orientation is antithetical to the core values of equity and solidarity that are central to a Canadian understanding of citizenship (Martin et al., 2018). It is also antithetical to (a) home care nurses’ core values and beliefs in caring, individual, and community participation; (b) principles of primary health care; (c) multiple ways of knowing; (d) individual and community partnerships; (e) environmental influences; and (f) empowerment in connecting with and caring for individuals, families, and communities (CHNC, 2011).
Ethics in the Everyday Lives of Clients, Families, and Home Care Providers

Many researchers have identified issues in home care that have arisen because of systemic problems (Ganann et al., 2019; Mohammed et al., 2018; Yakerson, 2019). These issues have not always been conceptualized as ethical in nature, but they are of ethical importance to nurses, because they reflect conflicting values, and they affect the health and well-being of care recipients and caregivers. In the following narrative and discussion, we draw on these issues to describe the ethical implications of neoliberalism.

In Ethics in Practice 13-1, a nurse describes many of the consequences of neoliberal health policies.

ETHICS IN PRACTICE 13-1

Narrative of a Home Care Case Manager: Self-Care and Family Care

I have been a case manager at a home care agency for the past five years. Before that, I worked in the ICU at a teaching hospital. I used to think that I had seen pretty much everything in terms of ethical problems, but I was really wrong. The community is very different and there are complex issues that I just can’t seem to resolve. There are cases that bother me so much that I feel that I can’t work here much longer. When I was in the ICU, although sometimes beds were an issue, we still always seemed to be able to have enough to go around. Here in the community, I find that there are never enough resources for everyone. Sometimes, we have clients who are so sick that we need to help them get admitted into hospital. The problem is that they are generally discharged just a few days later. Some of these people just can’t take care of themselves or don’t have family around. I feel terrible that we can’t provide them with the care they need because we can only give each person so much time.

One client, I’ll call him Joe, was one I have really tried to help. He was diagnosed with schizophrenia and type 2 diabetes and had few supports available to him. He came from Kenya eight years ago with his family when he was 15 years old, but started to get sick a few years later. After a short hospitalization last spring, we did our best to address his medical, psychiatric, and social needs, but the services available are so limited and fragmented. Joe needed many things that we found difficult to find for him, such as job training and a sense of belonging. His mother called the other day to tell us that he was not doing well again, and she is having difficulty coping not only with his symptoms, but also financially, because she has needed to take time off from work to care for him.
Expenditures for home care services have not met the increased demand for them; instead they are paid for either out of pocket, or by private insurance (Gilmour, 2018a); otherwise, the needed care is provided by family members. Many people who are sick or disabled must rely on themselves or their families and friends, if available, to provide care. This home care nurse is in moral distress as she describes the experience of wanting to provide care, but being incapable of doing so because the resources are simply not available. On the one hand, the nurse is attempting to help Joe attain the highest level of health possible for him, consistent with expectations in the Canadian Nurses Association’s (CNA) Code of Ethics for Registered Nurses (CNA, 2017). On the other hand, they cannot meet the ideals of practice, given the lack of available services to help promote Joe’s health. They are concerned that the mother is having difficulty coping with the demands of caregiving, which include not only physical and emotional demands, but also financial ones. The greater financial demands placed on caregivers reflect the declining involvement of governments in providing services, and the need for better integration of health and social services.

This nurse’s experience is also consistent with those reported in a recent Canadian study: Webber et al. (2021) interviewed community service providers, including nurses as well as other providers who conduct assessments for care, coordinate care, and monitor care delivery. The authors discovered that the community service providers were experiencing significant moral distress. This distress was a response to the constraints they encountered in the form of human resource challenges, which resulted in a lack of timely and adequate care. They also experienced powerlessness in a health care system they believed to be overwhelmed and unresponsive. Webber et al. argued that the underlying problem is that the community service sector has grown tremendously but has done so without a commensurate growth in funding.

As the nurse in Ethics in Practice 13-1 suggests, others must be there to provide care when professional government-funded home care services are not available or are limited. Canadians with high incomes may be able to purchase their own professional services, but, for most Canadians, the onus falls on family members to provide care for their loved ones. It is estimated that 25% of
Canadians care for either a family member or a friend with a serious health condition, many taking time off from work, using personal savings, and experiencing emotional difficulties and a decline in their own health (Parry, 2019; Statistics Canada, 2020). Canadians with low incomes can be particularly affected because often, they cannot take time off work, and do not have extended health care benefits to cover the cost of pharmaceuticals and additional home care services. Furthermore, many Canadians are experiencing homelessness, or live in homes that are not suitable for caregiving, such as crowded or poorly heated spaces.

The central role of socio-economic status, as well as other factors, such as immigration status, that impact people’s access to high quality home care services is evident upon reviewing the work of Canadian researchers on the subject. Based on a large population-based survey, Yung (2020) noted that recent immigrants to Canada were more likely to report unmet home care needs when compared to long-term immigrants and non-immigrants. Yung (2020) suggested that recent immigrants were more likely to rely on informal networks than access formal home care services because of language barriers and a lack of knowledge about the system. In another study of clients receiving palliative home care in Toronto, Wales et al. (2020) reported that clients with lower incomes were less likely to die in the home than those with higher incomes. Clients with lower incomes were significantly more likely to die in an acute care unit or in an in-patient palliative care unit. Although more research is needed in this area, the authors theorized that it might be more difficult for families with lower incomes to balance the demanding duties needed to support a loved one dying at home with work responsibilities and the need to financially support the family unit (Wales et al., 2020).

The transfer of caregiving responsibilities from governments to the family also represents the government’s reliance on the assumption that women will be available to care for others in the home, as Joe’s mother in Ethics in Practice 14-1 illustrates. In an ethnographic study of hospice and palliative home care, Sutherland et al. (2018) observed that traditional and inequitable gender roles were often reproduced when nurses negotiated caring duties with family caregivers, where men were often overlooked as legitimate
providers of comfort and caring work. In Canada, the greatest burden of both informal and formal care delivery falls upon women (Sutherland et al., 2018). The level of care provision can be extraordinary, encompassing both personal and high-tech care. It can include assistance with activities of daily living, such as bathing, eating, cooking, laundry, cleaning, and transportation, as well as the provision and management of medications, injections, intravenous therapy (IVs), catheterizations, dialysis, tube feeding, and respiratory care. These informal caregivers provide up to 80% of the care that community-dwelling older adults receive, contributing the equivalent of $25 billion dollars of unpaid work to the Canadian health care system (Caregiver Solutions, 2021).

Based on the studies above, addressing the underlying social injustices in Ethics in Practice 13-1 has the potential to make the greatest difference for Joe and his mother. It could be helpful to refer them to an available community service, where their socio-economic and immigration status, as well as Joe’s persistent mental illness, would be considered. Challenging the service deficits in home care at a policy level should be undertaken by advanced practice nurses and other nurse leaders, likely within the context of participation within a professional organization.

The Ethics in Practice case that follows shows that home care must be improved not only for patients and their families, but also for the home care workers who help these clients.

The working conditions of this home care worker reflect the competitive and economically focused nature of a health care system that rests on the neoliberal values of cost-savings and

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**ETHICS IN PRACTICE 13-2**

**Working Conditions of a Home Support Worker**

I used to be a physician in Brazil, but I haven’t been able to pass my exams here in Canada. My husband, who used to be a teacher, is unemployed, so I need to work as many hours as I can as a home support worker. Most of the people I take care of are very happy to see me, but I find the work heavy, not well paid, and there is a lot of travel around the city on the bus, even at night. Sometimes people talk to me like I don’t know anything, but I need this work for my family to live.
efficiency over good working conditions. This worker, like most formal home care workers in Canada, is an unregulated health care provider. Home health aides, attendants, and support workers are mainly women, many of whom are drawn from immigrant and visible minority populations. Although many community workers, including regulated health care providers such as nurses, enjoy the autonomy and varied work environments that providing home care can offer, they generally work alone without the assistance and team support normally available in institutional settings. They encounter threats to their personal safety, including physical and verbal abuse, unsafe neighbourhoods and travel conditions, and physical and emotional strain. Along with concerns regarding safety, home care work is often poorly paid, is seen as low status, and must be completed within highly constrained time periods (Ganann et al., 2019; Peter & Liaschenko, 2014).

The poor employment opportunities for this home care worker and their husband in Ethics in Practice 13-2 may also reflect the lack of community supports offered to them as they attempt to adapt to a highly competitive society that expects autonomy. Biases related to foreign credentials and language may make them less capable of competing with others. Bias against foreign credentials can manifest at both a personal level (i.e., preferential hiring or refusal of service from Canadian patients) and an institutional level (i.e., professional organizations and regulatory bodies refusing to recognize foreign credentials). Consequently, poorly paid home care work may be one of the few options available to immigrants with foreign credentials. Lightman (2021) has documented the feminized and racialized patterns of migrant and immigrant women working in low-status care, such as home care, in addition to the wage penalty that is commonplace in this sector in Canada. Ultimately, this economic arrangement, along with the unpaid work of family, permits the health care system to continue to function in an efficient but exploitative manner.

Nurses, particularly those in leadership positions in home care provider agencies, can help address these working conditions by attending to workload, travel arrangements, scheduling, and potential discrimination and safety concerns in homes. Providing a forum for workers to bring their suggestions for an improved work-
ing environment could also be helpful. Drawing attention to some of these concerns when budgeting and seeking further funding could also be important.

Our third Ethics in Practice case raises questions about how high-tech care has changed the responsibilities a home care nurse has for clients and their families.

**ETHICS IN PRACTICE 13-3**

**Nurse-Client-Family Relationships**

Over the years my role as a home care nurse has changed dramatically. I used to provide a lot of hands-on care, but now I mainly teach clients how to provide the care themselves. The other day, I taught a 91-year-old woman how to provide a complicated dressing for her husband and how to watch for signs of deterioration in his condition. I know she wasn’t comfortable doing this and has difficulty, given her own health problems. Unfortunately, they do not have internet and lack computer skills, so they cannot benefit from recently introduced virtual supports offered by my agency. They also require help with fundamental things like housekeeping and groceries. Although I think she is managing, I find myself worrying about them as soon as I leave.

The nurse in Ethics in Practice 13-3 describes the responsibilities of home care nurses with clients in the community who have increasingly more complex health issues, often living with several chronic illnesses. The introduction of additional “high-tech” care has also changed the relationships among the nurse, client, and family. The nurse teaches the client and family how to care for themselves and then takes calls to troubleshoot and problem solve. The client and family become more self-sufficient, and the nurse’s role becomes less hands-on, which for some clients may be desirable, but for others, such as the couple in the example, may be an enormous burden. The relationship eventually takes place at a greater distance, with the nurse acting as more of a resource than a direct caregiver. Technology, such as telemedicine, has the potential to enhance the abilities of health care providers, families, and friends to support community-dwelling older adults. Some have argued that this technology can create the “death of distance,” reduc-
ing social and physical barriers (Andrews et al., 2013). While not ideal, given older adults’ fear of losing physical contact with others (Sundgren et al., 2020), technology can make possible what previously would not have been possible at all, including greater frequency of nurses’ support, even at a distance.

Depending on the resources of the client and family, however, this type of relationship, with nurses acting more as resources rather than direct caregivers, may or may not adequately support the well-being of all involved. In other words, the individual situations of clients and families must be considered. In our current health care system, however, nurses may not have the time or resources to account for individual circumstances. In keeping with neoliberal trends, clients and their families must often take responsibility for their own care, even when they do not have sufficient resources to do so.

In fact, many of the responsibilities of family caregivers are those that previously would have been held only by regulated formal caregivers. Families often assume the responsibilities and perform many of the skills of registered nurses, but are not given the education, remuneration, or regulated working conditions and protections of formal providers. Because this occurs in the home, it can easily be hidden and justified as merely an extension of “usual” family responsibilities. Caregivers are profoundly affected by this work, to the extent that they experience increased morbidity and mortality (Parry, 2019). One in three family caregivers are reported to be distressed, given the profound impact on them emotionally, mentally, financially, and physically. Caregivers who assist someone who requires physical care, or who has communication and behavioural difficulties or dementia, are especially likely to be distressed (CIHI, 2020). Family caregivers who live in the shelter system, transitional housing, and unsafe housing conditions often face additional challenges as a result of balancing their responsibilities as caregivers with dealing with their own structural vulnerability (Stajduhar et al., 2020).

The demands placed on caregivers were illustrated in a qualitative study conducted in Ontario by Mohammed et al. (2018). These researchers examined the experiences of family caregivers following the home death of their family member from advanced
cancer and considered how caregivers interacted with the home care system. Family caregivers not only had to provide physical care, such as bathing and turning, to people who were dying, but also had to take charge of the organization and administration of home care because of system fragmentation, the lack of care continuity, and disorganized care services. Despite their lack of education, training, and information, family caregivers had to assume control of four main functions in their roles: (a) navigating the system; (b) engaging with professional caregivers; (c) preparing for death; and (d) managing after death. Family caregivers reported having to contend with their own emotional despair and helplessness, while simultaneously having to access and manage the consistency of home care staff in a system where family and clients’ needs were not met. Family caregivers were constantly required to initiate care services. Reflecting the downloading of public responsibilities, family caregivers believed that they had to take control, particularly to oversee complex care needs at the time of death and the period shortly afterward, because few home care professionals had oversight concerning the overall process of dying in the home.

Mohammed et al. (2018) effectively illustrated how the neo-liberal policies of home care in Canada have shaped the everyday lives of clients, families, and home care nurses. Home care recipients and their caregivers are often without the necessary resources to receive and provide care in such a way that the well-being of all involved is maintained. Every aspect of the work of home care nurses has been impacted. This situation compromises the ability of nurses to enact one of nursing’s most fundamental ethical values—the requirement to promote the health and well-being of persons (CNA, 2017). Nurses can advocate for further services at a local level, including respite care, whenever possible, to support clients such as those in Ethics in Practice 13-3. Advanced practice nurses and other nurse leaders must also develop and promote strategies for broader changes in Canadian home care policy such that care recipients and their families are protected and nurses can practice ethically.
Recommendations for Nursing Practice, Policy, and Future Directions

In the CNA’s 2019 document *Advanced Practice Nursing: A Pan Canadian Framework*, leaders in Canadian nursing suggested that APNs should be able to “explain and apply the theoretical, empirical, ethical and experiential foundation of nursing practice” (p. 14). As a result, nurses who practice in advanced roles must be attuned to the ethical and theoretical contexts that have led to the current state of home care in Canada. The document outlines several advanced practice competencies, such as direct comprehensive care, optimizing health systems, consultation, collaboration, and leadership (CNA, 2019). Although several are transferable to nursing practice in home care, optimizing health systems where APNs “contribute to system-level change through policy and guideline development and effective use of resources” (CNA, 2019, p. 31) provides directions for improving the access to and quality of home care.

In home care policy, like other forms of policy, the values of the politically dominant group are expressed; consequently, policy has a moral dimension that entails values, power, and ideology (Kenny & Giacomini, 2005). Current Canadian home care policy reflects the values and beliefs consistent with market justice and individualism (Yakerson, 2019). As such, home care policy rests on a neoliberal notion of citizenship. This dominant vision of reality can be resisted: in recent years, several Canadian authors have offered alternative views. For example, Sherwin and Stockdale (2017) argued that a feminist relational approach can help people recognize the impact of systemic patterns of privilege, dominance, and power. Awareness of these patterns should inform policy decision making, as well as collective strategies to address urgent issues related to health. Sherwin and Stockdale urged that people consider key moral concepts, such as justice, responsibility, and solidarity, through a relational lens. This kind of approach, when used in policymaking, has the potential to uncover the harmful impact of individualism in home care policy. The use of a relational lens could also lead to a view of health care as a collective responsibility because it underscores the interdependence and need for care of all people.
Varcoe and Rodney (2009) and Varcoe et al. (2004) have described how the underlying ideologies of scarcity and corporatism—the movement toward corporate values and structures in the delivery of health care services—have had a constraining influence on nurses’ moral agency. They offered examples of nurses who have resisted these ideologies in a variety of ways, including through the negotiation of better care, relationship building among workers and clients, and rule bending. They suggested strategies of further resistance that go beyond individual efforts. These included the restructuring of nurses’ work in ways that align with the goals of health and the common good instead of the goals of corporatism. They also recommended unmasking current ideologies and the values underlying these ideologies, so that nurses can become more conscious and deliberate about their own values. Innovative and politically savvy nurse reformers may lead in realizing some of these goals. More likely, however, change will be made possible through the everyday activities of nurses who adopt the strategies noted above by Varcoe and colleagues. We must guard against the tendency prevalent in nursing of either viewing nurses as powerless or of viewing power as somehow separate from the usual activities of nurses.

Peter (2002) examined the politics of home care by exploring how early-20th-century private duty nurses practicing in homes exercised power. Despite the emphasis in nursing upon duty and obedience to physicians at that time, nurses also plainly expressed their capacity to influence their clients through education, role modelling, and creating order in homes. Private duty nurses later played a significant role in the rise of hospital utilization and thus, like nurses today, they were not powerless. Their values left a mark not only on individual clients and families, but also on the health care system as a whole. Therefore, purposefully explicating our current values may foster a much-needed awareness that can move us collectively forward to a more humane and ethical home health care system, as well as other care delivery sectors.

Peter et al. (2007) analyzed home care policies across Canada. They generated a preliminary ethical framework which can be used by nurses to examine and develop home care policy and to direct practice. The framework includes the dimensions of relational
autonomy, care, and social justice. Social justice is of particular importance because it can counter the predominance of market justice inherent in neoliberalism. Attention to social justice is required to promote a belief in collectivism over individualism. Consequently, home care policies that idealize autonomy and independence need to be critiqued because many Canadians have care needs that cannot be met by themselves or their families alone. It is important when nurses are in a position to influence policy that they consider the underlying values of policies such that the needs of home care recipients along with those of their family members and caregivers are met.

Striving for social justice often requires collective action to reduce the effects of factors such as age, disability, and poverty on people’s abilities to access resources that promote health. Promoting awareness and action regarding human rights, homelessness, poverty, unemployment, and stigma, for example, are ways of working toward social justice. Young (2011a; 2011b) recommends forward-looking strategies using the social connections among us; because many of the issues underlying the problems that are inherent in home care policies and delivery have structural roots, it is difficult for individuals alone to make significant change. Nurses have the benefit of belonging to organized nursing groups that have the potential to make social change (Peter, 2011). It is important that codes of ethics in nursing, such as the 2017 CNA Code of Ethics for Registered Nurses, continue to provide a vision of social justice that nurses can use as an ideal. While making social change is exceedingly difficult, progressive small steps forward are important. For example, the Canadian Nurses Association, the Canadian Home Care Association, and the College of Family Physicians of Canada joined together to author a report in 2016, entitled Better Home Care in Canada: A National Action Plan (Better Home Care Partners, 2016), which provided a vision of an improved home care system. The three organizations called for many transformational changes to the current system, based on principles, standards, accountability, and evidence. Through a range of short, medium, and long-term goals they envisioned a system that would create better access to care, sustainable funding, the recognition of the role
of family caregivers as partners in care, and the expansion of the use of information and communication technology.

Opportunities also exist for nurses to become engaged with respect to issues of social justice. Writing letters to local Members of Legislative Assemblies or Members of Parliament, and participating in activities of professional nursing organizations, are credible and pragmatic ways to have influence. Nurse educators in undergraduate and graduate nursing programs can also foster an understanding of social justice for future and current nurses. Students should become sensitized in the classroom and in clinical practice to the health concerns of marginalized groups, and to the need not only to equitably distribute health care services, but also to pay attention to the social determinants of health. The 2017 CNA Code of Ethics can be helpful in this regard. The CNA advocates that nurses promote social justice through a variety of actions, including (a) changing systems and societal structures; (b) incorporating the principles of primary health care; (c) working with others to change unethical policies; (d) recognizing the importance of the social determinants of health; and (e) advocating for access to the full continuum of health care services for all.

### Moving Toward an Ethics of Social Justice in Home Care

In this chapter, we have described the current state of home care in Canada, revealing the inadequacies and inequities that lead to a home care system that too often does not meet the care needs of Canadians. The changes in home care are the result of not only advances in technology, but also neoliberal beliefs in market justice and individualism. We have provided recommendations, based on a social justice framework, that have the potential to counter the market justice focus of neoliberalism.

### QUESTIONS FOR REFLECTION

1. How has neoliberalism affected your nursing practice?

2. What are the ethical dimensions of health care policy? How can nurses challenge unethical policies?
3. *Is an emphasis on social justice in nursing ethics compatible with the traditional ethical ideal of the caring nurse-client relationship? Why or why not?*

4. *With the current emphasis upon acute care in home care provision, how can nurses ensure that the well-being of those with disabilities and chronic illnesses is protected?*

5. *How can advanced practice nurses and other nurse leaders best contribute to improving the home care system in Canada? What strategies should be employed?*

6. *Why are nurses well positioned to have a significant impact in this endeavour?*
Endnotes


2. See Chapter 3 in this textbook for more information about the role Canada’s provinces and territories play in health care.

3. See Chapter 15 in this textbook for more information about seniors in long-term care.

4. Chapter 3 in this textbook provides information about the details of the CHA.

5. For more explication of social justice and intersectionality, see Chapter 1 in this textbook.

References


Canadian Institute of Health Information. (2020). 1 in 9 new long-term care residents potentially could have been cared for at home. https://www.cihi.ca/en/1-in-9-new-long-term-care-residents-potentially-could-have-been-cared-for-at-home


CHAPTER 14

The Ethics of Caring for People With Disabilities

Sandra Marquis and Jennifer Baumbusch

“Disability doesn’t make you exceptional, but questioning what you think you know about it does.” (Young, 2014)

There is considerable evidence that disabled people experience stigma, exclusion, and discrimination when accessing health care. Many highly contested and debated issues in health care have their origins in the treatment of people with disabilities. Policies and procedures rooted in eugenics—including forced sterilization, rationing of care services, institutionalization, “mercy killings,” and more recently, prenatal testing—are past and current issues impacting this population. These disability-related issues are a result of cultural assumptions and biases about disability and disabled people. How people think of disability affects how disabled
people are treated in the health care system. Drawing upon the words of Stella Young, the Australian comedian, journalist, and disability rights activist quoted at the beginning of this chapter, we contend first that nursing practice and leadership in the health care of disabled people requires education regarding disability. Currently, the lack of disability content in nursing curricula is well-documented. Secondly, nurses must apply this knowledge to interrogate cultural norms and biased health care practices surrounding disability.

We start this chapter by describing language used to refer to disability and disabled people. We then discuss definitions of disability and prominent models of disability that will form a foundation for understanding how disabled people are treated in the health care system. Next, we consider disability in the context of a number of health-related issues throughout a disabled person’s life. Finally, we consider ways to move forward in partnership with disabled people to address harms they have experienced individually and as a community in relation to health and health care services.

**Speaking of Disability: The Importance of Language**

The terminologies and language surrounding disability are important and have evolved over time. In the past, terms such as “slow,” “idiot,” “moron,” “handicapped,” “impaired,” and “retarded” (the “r” word) have been socially acceptable and included in medical terminology. These terms are no longer acceptable and are considered offensive (Degeneffe & Terciano, 2011; Special Olympics, n.d.). Currently, three main types of language are used to refer to disabled people: person-first language, identity-first language, and terms used when people reject or modify the term “disability” entirely (for example, “diversability”).

In North America there is often an emphasis on person-first language. Person-first language arose in relation to the *Americans With Disabilities Act* in the United States (Burgdorf, 1991). Person-first language refers to identifying the person first and then the disability, making the point that the person is a “person first.” Using this language, people are referred to as “a person with a disability,” “a
person who has Down syndrome,” or “a person who has schizophreneia.” Terms which forefront or primarily define the person by their impairment—such as referring to someone as “an autistic boy” or “a schizophrenic”—are not acceptable in person-first language.

Identity-first language is used outside of North America. Identity-first language is used to emphasize that people are disabled by their social and physical environment, not by their individual impairment. While someone’s impairment (for example, having a spinal cord injury) is an individual property, disability is created by external societal factors, such as a lack of wheelchair access to the workplace. In identity-first language, the term “disabled people” is acceptable, as a person’s disability is seen as an important and persisting aspect of their life. Within North America the use of person-first language has become contentious, with advocates maintaining that rather than equalizing treatment of disabled people, it contributes to stigma (Gernsbacher, 2017). This debate, plus a growing emphasis on disability pride, and on claiming disability as a vital part of a person, have contributed to the increased use of identity-first language over person-first language in North America.

In British Columbia, a third type of language is used in relation to people who have intellectual/developmental disabilities (IDD). The term “diversability” was coined in 2007 by Tiffany Yu (Yu, 2022) to refer to people with all types of disabilities, and was adopted in 2012 by self-advocate Shelley DeCoste to refer to people with developmental disabilities (Community Living British Columbia, n.d.). The term “diversability” has grown in popularity across British Columbia. The Deaf community also resists the label of disability and considers themselves to be a distinct culture with their own language (sign language) and values (Canadian Association of the Deaf - Association des Sourds du Canada, n.d.). In this chapter, we have chosen to use identity-first language to emphasize the importance of disability for individuals. However, when nurses are interacting with an individual, it is important to ask them about their language preference.

There are other important language issues to consider. Referring to people who do not have disabilities as “normal” or “typical” implies that disabled people are not normal or typical; therefore, a better term for people who do not have disabilities is “non-disabled
people.” The framing of a person’s adaptive equipment, such as crutches, wheelchairs, or walkers, is also important. Equipment should be described as something that assists but does not limit the person. For example, “uses a wheelchair” is acceptable, while phrases such as “confined to a wheelchair” or “wheelchair-bound” are not (McCain, 2017). In addition, describing disabled people as “victims” or “suffering” (for example, the patient is “suffering” from blindness) is inappropriate (Laithland, 2019). When using these terms, people assume that the disabled person has a poor quality of life; such assumptions are based on biases that are often incorrect.

The terms “ableist” and “ableism” are used to refer to societal biases (Harpur, 2012). Ableism has been defined as discrimination in favour of the able-bodied, and includes the idea that disabled people are inferior to non-disabled people (Linton, 2006). Ableism is a type of discrimination, just as sexism and racism are. Ableism can be found in every facet of society, including language, media portrayals of disabled people, the built environment, political structures, economics, education, and health care. Nurses, too, are influenced by societal biases. Nurses should be aware of how they refer to disabled people and their assistive devices in their speech, and in health records and documentation. In sum, nurses need to understand how disabled individuals self-identify and take up the appropriate language of disability in order to provide and promote person-centred care.

**Defining Disability**

Defining disability is complex. Is disability an illness, an impairment, a result of social stigma, or a cultural construct? The *Oxford English Dictionary* defines disability as “lack of ability; inability, incapacity; weakness or a physical or mental condition that limits a person's movements, senses, or activities” (“Disability,” 2021). This definition is premised on the idea that disability represents a personal lack of something (physical, developmental, etc.), and is primarily based on a medical view of disability, which relies upon a diagnosis obtained from a trained professional. (Please read a further discussion about this in the section below under the heading “The Medical Model.”)
The United Nations has a more complex and nuanced definition of disability. According to the Preamble to the United Nations Convention on the Rights of Disabled Persons (2008), disability “is an evolving concept and disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others[.]” (United Nations, 2008, para. 5). To reflect the complexity of defining disability, the WHO (n.d.) has provided an International Classification of Functioning, Disability and Health (ICF). Replacing the OED’s definition of disability as a condition causing mental or physical limitation, the ICF provides a broader functional definition of disability that includes individual body functions and structures, and distinguishes between individual activity limitations and participation restrictions imposed by society.

Using the terminology in the ICF, an impairment is defined as a problem in body function or structure. An activity limitation is a difficulty encountered by an individual in executing a task or action, while a participation restriction hampers an individual’s involvement in life situations. Since everyone’s functioning occurs in a context, the ICF also includes recognition of a wide variety of environmental factors that can influence the experience of disability. These environmental factors include physical factors such as terrain and building design, as well as social factors such as laws and societal attitudes. By including these factors, the authors of the ICF also take into account the social aspects of disability and do not see disability as a “medical” or “biological” issue alone. The ICF authors stress that disability is not something that only happens to a minority of humanity, but instead recognize disability as a universal human experience.

**Conceptual Models of Disability**

Many conceptual models have been proposed as a way to better understand how disability has been framed in Western culture. In this chapter, we discuss five of these models: the tragedy/charity model, the economic model, the medical model, the social model, and the biopsychosocial model. The tragedy/charity and economic
models, although now considered dated, continue to underpin many current structural inequities in care and personal exchanges between health care professionals and disabled people. In the last century, the two most influential models have been the medical model and the social model. We also acknowledge that there are other world views, such as Indigenous perspectives, which foster alternative understandings of disability.

The Tragedy/Charity Model

The tragedy/charity model of disability is used frequently in Western culture to frame disabled people as victims to be pitied. Disability as tragedy is a common theme in many stories, movies, and social media interactions. This model is also often used in fundraising campaigns and to justify services for disabled people; for centuries, sick and disabled children have been exploited for fund-raising (Longmore, 2013). In British Columbia, for example, the BC Lions Society for Children with Disabilities raised money for decades by portraying children with disabilities as pitiful during their annual Timmy Christmas Telethon fundraisers. However, this perspective does not account for the rights of disabled people, the strengths of disabled people, or for the role of society in disabling people.

The tragedy model is also evident in what Young (2014) described as “inspiration porn” (Young, video introduction). Inspiration porn refers to images and stories that portray disabled people as inspirational because they are disabled. It is based upon stereotypes of disabled people and is designed to inspire non-disabled people by creating a narrative that focuses on their apparent lack of limitation in comparison (that is, “if that poor disabled person can do it, so can I”). While inspiration porn and stereotypes contribute to a limited view of disability and disabled people that affects how they are treated, disabled people are counteracting this narrative. As Young (2014) states, “I am not your inspiration, thank you very much.” The WeThe15 international coalition of organizations is also working to change attitudes regarding disability. We encourage readers to watch their video (WeThe15, 2021).
The Economic Model

The economic model is used to describe disability in terms of an inability to be “productive,” depicting disabled people as a burden on society’s resources. In North America, people are valued for their autonomy and independence (Macpherson, 1962; Stramondo, 2016), and according to theories of utilitarianism, for their contributions to society (Sullivan, 2009). Individualism and independence are idolized in media, myths, and societal emphases on attainment. This creates a cultural bias against disabled people, as many are not independent in the ways that the dominant North American culture defines independence (Davis, 2013; Reinders, 2000). They also may not be “productive” in the traditional economic sense, such as following a particular career path or earning a large wage. Independence for disabled people may mean the use of devices, such as wheelchairs and feeding tubes, and having supported decision making. For disabled people, realizing independence is about securing the necessary tools (for example, wheelchairs, feeding tubes or supported decision-making) to be “able to achieve goals and have control over one’s life” (Stienstra, 2012, p. 104).

The cultural bias against people who are not perceived as independent and who do not “contribute” to society is also evident in hierarchies of disability. Researchers over the years have consistently found that both disabled and non-disabled people view disability as a hierarchy of impairments (Deal, 2003; Tringo, 1970), with the most negative attitudes focused on people with IDD (Irish Social Science Data Archive, 2017; Scior, 2011). This hierarchy of attitudes also exists among health care professionals. For example, Lewis and Stenfert-Kroese (2010) found that nursing staff had less positive attitudes about caring for a patient with an IDD than for a patient with a physical disability.

Parmenter (2001) argued that the emphasis on independence, even within disability advocacy, contributes further to the view of disabled people (especially those who have an IDD) as having lower status and less value than non-disabled people. Many disability advocates have turned instead to stressing the importance to
humans of interdependence and community; see, for example, the video *Examined Life* (Butler & Taylor, 2010).

**The Medical Model**

The medical model of disability is prevalent in Western medicine and society, and has had the largest impact on shaping both overall attitudes towards disabled people and health care for disabled people. In this model, disability is considered to be a health problem or abnormality caused by disease, genetics, or trauma that requires individual diagnosis and treatment. The focus is on the disabled individual’s limitations and the work required to “cure” the disability or to reduce the individual’s impairments so that the person can fit into society; in other words, to “normalize” the person (Davis, 2006). Use of the medical model assumes that there is a “normal” state of being, from which disabled people deviate. Davis pointed out that in North America and Europe, those who are part of the dominant culture have a cultural understanding of what “normal” means, and that acceptance of “normal” stigmatizes disabled people.

The medical model has contributed positively in the areas of prevention, cure, and reduction of disability. Examples of this include the discovery of a cure for leprosy and the introduction of seizure control medications. However, the medical model of disability has been criticized for its limitations and for its focus on individual cure or treatment (Goering, 2015; Roush & Sharby, 2011). Disability advocates argue that despite the many benefits of medicine and individualized services, use of this model often negatively affects the lives of disabled people. Negative effects include narrow definitions of disability, assumptions that disability is synonymous with “suffering” and a poor quality of life, an artificial emphasis on “normal,” control by professional service providers, segregation, and relationships of dependency in which the disabled person is the passive recipient of professional expertise (Goering, 2015; Hayes & Hannold, 2007; Roush & Sharby, 2011).
The Social Model

The development of the social model signalled a profound shift in disability discourse. In contrast to the medical model, in the social model, disability is conceptualized as socially constructed, not as an individual problem. The social model was developed in the United Kingdom in the 1970s as a direct rejection of the medical model and the “tyranny of the norm” (Shakespeare, 2006, p. 198). Advocates of this model focus on social oppression and environmental barriers (Oliver, 2009). They maintain that most problems encountered by disabled people are not a result of their bodies or capabilities, but, rather, are the result of a lack of acceptance by society, including society’s failure to provide the necessary supports. Key elements of the model are (a) a distinction between disability (defined as social exclusion caused by, for example, a lack of accessible buildings, or policies that create barriers to inclusion) and individual impairment (defined as a physical or intellectual limitation); (b) a recognition of disabled people as a stigmatized group; and (c) an emphasis on the removal of barriers (through anti-discrimination legislation, etc.) that cause disability (Shakespeare, 2006).

Use of the social model involves identifying systemic barriers, negative attitudes, and exclusion by society (either purposeful or inadvertent), thus emphasizing that society is the main contributory factor in disabling people. While individual impairments may be caused by physical, emotional, or intellectual differences, these do not have to lead to disability unless society fails to include all people (Withers, 2012). This emphasis on social exclusion shifts responsibility for change from a focus on the individual (curing or normalizing people using the medical model) to a focus on society (making society more inclusive).

The Biopsychosocial Model

The biopsychosocial model allows users to conceptualize disability as universal, and as an interaction between intrinsic factors (impairments) and environmental factors (activity limitations and participation restrictions) (Bickenback, 2012). This model is reflected in the ICF classifications of disability discussed earlier in this chapter. The biopsychosocial model was developed as a
response to the limitations identified for both the medical model and the social model of disability (Shakespeare & Watson, 2001), and through attempts by professional groups to distance themselves from the medical model and to include social aspects of disability (Hayes & Hannold, 2007; Roush & Sharby, 2011).

An important aspect of the biopsychosocial model is its emphasis on the universality of disability. Disability is not rare, nor is it an abnormality. For example, the disability rate in 2006 in Canada was reported as 14.3%, which represented 4.4 million Canadians. This disability rate steadily increased with age; Canadian seniors aged 65 and over had a disability rate of 43.4% (Statistics Canada, 2011). In *The Canadian Survey on Disability* (Statistics Canada, 2017), it was estimated that the prevalence of disability was one in five Canadians (or 6.2 million) aged 15 years and over. This is a marked increase over the 2006 data. The United Nations estimates that individuals in developed countries spend on average about 8 years, or 11.5% of their lifespan, living with disabilities (United Nations, 2008).

Each of the models of disability discussed in this chapter provides insight into how disability is viewed and how disabled people are treated. However, each model has limitations. For example, some disability theorists have maintained that the biopsychosocial model does not account for the oppression imposed on people with disabilities by societal norms and values (Thomas, 2004), and does not include a life course perspective of disability (Smith, 2002). Advanced practice nurses need to question and reflect upon how they may unconsciously be taking up the negative aspects of these various models in their practice.

**Additional World Views of Disability**

All of the previously discussed models of disability come from predominantly White, Western cultural perspectives. Disability is viewed differently by people in other cultures. Meyer (2010) described differences in terms of individualistic versus collectivist societies, with individualistic societies emphasizing individual resources and support and individual human rights, and collectivist societies emphasizing the importance of the family or cultural
Examples of Disability-Related Ethical Issues in Health Care

Building on the foundational content of this chapter, we now consider some prominent ethical issues in practice related to disability. As we have indicated earlier, many of the issues faced by disabled people in the health care system stem from how disability is defined and understood in dominant cultures and, subsequently, how these values become ingrained in the structure of health care systems. Health care programs, services, and decisions are often based upon the medical model of disability, with assumptions that disability is synonymous with a poor quality of life, that disabled people are a burden, and that some disabilities are more acceptable than others.

These assumptions are particularly evident in the relationship between disabled people and eugenics. Wilson (n.d.) defined eugenics as “the selection of desired heritable characteristics in order to improve future generations.” Wilson explained that eugenics was first described in 1883 and was influenced by Social Darwinism, including the concept of the “survival of the fittest.” Ideas about eugenics continued to expand until, by World War II, the Nazis were using eugenic theories to justify their extermination programs.

Policies and practices explicitly rooted in eugenics theory have existed in Canada for many years. Sexual Sterilization Acts were passed in Alberta in 1928 and in British Columbia in 1933 (Leung, 2012). These Acts allowed for the surgical sterilization of “defectives” without the person’s knowledge or consent. The aim was to promote a “healthy population while reducing the cost of these individuals
on the state” (Leung, 2012). “Defectives” included people with IDDs, people with physical disabilities, single mothers, Indigenous people, Métis, and Eastern Europeans (Leung, 2012). These Acts were finally repealed in 1972 (Alberta) and 1973 (British Columbia). In Alberta, 2,832 people were forcibly sterilized (Park & Radford, 1998). Forced sterilization of disabled girls and women continues to be legal in some countries, including Australia (Elliott, 2017; Simhan, 2019).

Eugenic ideas remain prevalent in current issues surrounding human reproduction and death, and have given rise to discussion of “new eugenics” (Brown, 2019; Reinders et al., 2019; Rembis, 2009). These authors maintain that there is very little difference between the old eugenics and new eugenics. New eugenics simply uses new techniques to obtain the same goal: the selection of particular human characteristics. Debates regarding new eugenics now centre on health-related issues, including gene manipulation (Benston, 2016), perinatal medicine (Garrett et al., 2017; Grue, 2010), selective abortion (Thomas & Rothman, 2016; Ville, 2011), do not resuscitate orders (Dyer, 2012; Neville, 2021), health care rationing (Andrews et al., 2021; Lund & Ayers, 2020), and medically assisted death (Duong, 2021).

**Perinatal and Neonatal Care**

Questions around perinatal practice—such as selective abortion and care of disabled newborns—epitomize many of the current ethical concerns regarding eugenics and disability. These issues are centred on the common cultural assumption that disabled children are a “burden from birth” (Rubeis & Steger, 2019). There are a number of ethical issues that advanced practice nurses should be aware of and consider through a disability lens. These issues include (a) the implications of reproductive genetic carrier screening, that is, testing people to determine their likelihood of having a child with certain disabilities (Dive & Newson, 2021); (b) prenatal screening and counselling; (c) selective abortion; and (d) discussions about whether or not extremely preterm newborns should be resuscitated (Garrett et al., 2017; Grue, 2010).

Ville (2011) pointed out that perinatal medicine plays an active role in the social treatment and perspectives of disability. The
selective abortion of Down syndrome fetuses is an example of this phenomenon (Zhang, 2020). Thomas (2016) reported that assumptions that Down syndrome reduces quality of life affect how HCPs provide information during prenatal screening consultations. Specifically, Down syndrome was a topic often avoided during consultations, as health care professionals believed they had minimal knowledge of the subject. In a study by Kellogg et al. (2014), 48% of mothers of children with Down syndrome believed that HCPs gave biased or incorrect information. Williams et al. (2002) questioned whether or not counselling attached to prenatal screening could be truly non-directive and unbiased, given cultural biases about disability and assumptions about the quality of life of disabled people and their families. As a result, disability activists have condemned selective abortion of disabled fetuses as evidence of the devaluing of disabled lives (Brown, 2019; Reinders et al., 2019). In Ethics in Practice 14-1 we present a scenario in which the biases of HCPs and their judgments about quality of life negatively affect the relationship between a mother and her newborn.

ETHICS IN PRACTICE 14-1

A Common Experience of Parents of Newborns with Genetic Differences

Working on a maternity unit, you enter your patient’s room to check on her and her newborn. The mother is lying on her side, facing away from the baby, and is crying. You gently ask how she is doing. She replies, “The doctor was just here and said ‘I’m sorry, your baby has Down syndrome.’ This didn’t come up in the prenatal testing. What am I going to do?”

In this Ethics in Practice scenario, the new parent is confronted with an unexpected diagnosis for her newborn, but the way the information was communicated—as an apology, implying that the baby is a burden—contributes to their distress (Canadian Down Syndrome, 2017). As advanced practice nurses, how do we support care for patients who receive unexpected news, and also support them to readjust their perspective on disability? How can we
address this situation with the provider who shared the diagnosis, as well as with other team members?

**Quality of Life and End-of-Life Care**

Cultural assumptions that disabled people have a poor quality of life commonly affect health care practices. “I would rather be dead than live with a disability,” is a sentiment that disabled people, particularly those with severe disabilities, hear from people without disabilities” (Wiebe & Derksen, 2010, Executive Summary, para. 1). Wiebe and Derksen add, “Incorrect assumptions about quality of life have the power to trigger responses that harm people with disabilities” (Executive Summary, para. 1). This sentiment of fear stands in stark contrast with the actual lives and experiences of many disabled people. As Withers (2012) explains:

> Our disabled identities are important to many of us. While I am in incredible pain at times, I value the things that I get from my body—a body that is considered disabled. I appreciate my slow labored walk because I notice things that many other people don’t. My pain and my inability to do certain things also makes me very efficient, skilled at delegation and thoughtful about help and asking for it. These are parts of my personality that I am proud of and couldn’t imagine living in the world without. (p. 48)

Evidence of incorrect assumptions about quality of life that harm disabled people can also be found in the history of “do not resuscitate orders” being applied to disabled people without their consent or knowledge (Dyer, 2012; Neville, 2021; Wagemans et al., 2017). Disabled people have also expressed fears that decisions regarding medical assistance in dying (MAID) will be influenced by cultural biases that regard disabled people as suffering, having a poor quality of life, and being a burden on the health care system (Duong, 2021). The protection of vulnerable persons regarding MAID has generated much concern among disabled people and disability advocates (Council of Canadians with Disabilities, 2021; Philpott & Wilson-Raybould, 2020; Vulnerable Persons Standard, 492 Toward a Moral Horizon
2017). In end-of-life care, there is also evidence of the devaluing of disabled lives. In general, disabled people experience poor access to palliative care services in comparison to the non-disabled population (Adam et al., 2020; Tuffrey-Wijne et al., 2016). In Ethics in Practice 14-2, we present a scenario in which a frightened patient expresses the common attitude of “better dead than disabled.”

**ETHICS IN PRACTICE 14-2**

*Responding to Traumatic, Disabling Life Events*

While working on a surgical ward, you have a 21-year-old patient who has been in a snowboarding accident and has been diagnosed with a spinal cord injury that will limit his mobility. He appears depressed and refuses to speak to his physicians or to his family. When you come into the room he yells “I want to die! Why didn’t you let me die? Someone help me die!”

In Ethics in Practice 14-2, you are confronted with despair and suicidal ideation that can be common among people newly diagnosed with spinal cord injuries (Spinal Cord Injury Canada, 2020; Tchajkova et al., 2021). According to Rodríguez-Prat et al. (2017), some of the most common reasons that people consider physician-assisted death include fears regarding loss of independence, uncertainty regarding the future, and concern that they will be a burden for their loved ones. As advanced practice nurses, we can provide much needed support for patients as they adjust to changed life circumstances and fear of the unknown. We can help patients navigate these fears and consider how they may stem from cultural concepts and biases about disability rather than the lived experience of many disabled people.

**Inequities in Health Care Throughout the Life Course**

Disabled people experience well-documented inequities in access to and provision of health care throughout their lives. This is particularly evident for those disabled people who are considered to be lower on the hierarchy of disabilities; that is, people with (IDD). One
well-documented issue is screening for common medical conditions. Compared to people without IDD, those with IDD experience lower rates of screening for hypertension (Hanley et al., 2021; O’Brien et al., 2021; Schroeder et al., 2020), osteoporosis (Burke et al., 2017), breast cancer (Cuypers et al., 2020), cervical cancer (Brown et al., 2016; Cuypers et al., 2020), and colon cancer (Cuypers et al., 2020). In addition to lower rates of screening and under-diagnosis of cancers, Cuypers et al. (2020) found that people with IDD who were diagnosed with cancer were under-treated.

Additional examples of inequity in health care for people with IDD include poor hospital experiences and neglect of pain management. Several authors have documented poor hospital care, including delays in care, lack of consistent care, and poor communication among staff regarding hospitalized patients with IDD (Iacono et al., 2014; Tuffrey-Wijne et al., 2014). Neglect of pain management occurs frequently in adults with IDD. Weissman-Fogel et al. (2015) found that 48% of adults with IDD experienced chronic pain, and 10% experienced high levels of chronic pain. This chronic pain was due to a need for adaptation of wheelchairs; lack of care for digestive, oral/dental, and orthopaedic conditions; and a lack of availability of analgesics for menstrual pain. Further, Rush (2013) noted that poor dental care has been a well-documented source of pain for disabled people, particularly people with IDD.

In Ethics in Practice 14-3, we illustrate some of the difficulties in providing accessible care and offer some suggestions to increase one aspect of accessibility.

**ETHICS IN PRACTICE 14-3**

*Making Emergency Care Accessible*

A mother takes her seven-year-old autistic son into the emergency department because he has cut his hand on a piece of glass. It is not a deep or serious wound, but it is continuing to bleed. The child is visibly agitated. He paces in the waiting area, giving intermittent cries and waving his bleeding hand. It is Friday evening, the waiting area is full, and the wait times are four hours or more. As time passes, the child becomes more and more agitated. He lies on the floor and starts to emit an ear-piercing scream. Other patients in the waiting area are complaining about the noise.
There is evidence that existing disparities in health and health care for disabled people have been exacerbated during the COVID-19 pandemic. For example, in Canada, COVID-19 positivity rates were 1.28 times higher for adults with IDD, and 1.42 times higher for adults with Down syndrome, compared to non-disabled adults (Lunsky et al., 2021). Lunsky also reported that adults with IDD were more than twice as likely to be hospitalized and to die following a COVID-19 diagnosis. For adults with Down syndrome, mortality rates were 6.59 times higher than those without IDD. This inequality has also been reported in other countries (Clift et al., 2021; Landes et al., 2021). In England, for example, researchers found that compared to non-disabled people, people with intellectual disabilities had a 56% increased risk of dying from COVID-19 after they were hospitalized (Baksh et al., 2021). These authors attributed this increase in death rate to bias and discrimination that lead to disparities in care. They found that people with intellectual disabilities admitted to hospital with COVID-19 were 37% less likely to receive non-invasive respiratory support, 40% less likely to receive intubation, and 50% less likely to be admitted to the ICU.

During the COVID-19 pandemic, disabled people also experienced greater barriers in accessing services for their ongoing health care needs. In a study of children with medical complexity in British Columbia, Canada, Baumbusch and colleagues (2022) found that children had a significant decline in access to allied health therapies.
(for example, physiotherapy, occupational therapy, speech and language therapy) and medical specialists during the initial wave of the pandemic. Additionally, Baumbusch and colleagues found that single-parent families were less likely to take their children to the emergency department than they would have prior to COVID-19. This reluctance to access emergency department services reflected the impact of public health measures, which, at the time (March to August 2020), severely restricted the number of essential care partners who could be with a patient in the hospital. One tragic outcome of these restrictions was the death of Ariis Knight, a disabled woman in BC whose family and support workers were not permitted to be with her during a hospitalization early in the pandemic (Bains, 2020).

**Responses from Nurse Leaders**

Addressing health inequities and preventing harm to disabled people will require intentional and authentic engagement by the nurses providing direct care, as well as nurse leaders. Two core practices that form the basis for this engagement include understanding common cultural views of disability and their effects on disabled people, and partnering with disabled people to work towards transformation of individuals’ health care practices, as well as health care systems and policy. “Nothing about us without us” (Charlton, 1998, p. 1) is a well-known disability rights slogan, and must be central when considering how to move forward. Disabled people should have increased visibility, both as advisers to health care policy and practices and as teachers in health care education settings. Building on these core practices, we follow through with a discussion focusing on nursing education.

**Nursing Education**

The lack of disability content in nursing curricula is well-documented, and contributes to critical inequities that arise from inadequate education of nurses and other HCPs (Cashin et al., 2021; Lewis & Stenfert-Kroese, 2010; Ndengeyingoma & Ruel, 2016). Nursing curricula should include disability-related topics in undergraduate, graduate, and continuing education programs. We need
to question how we perceive disability—for example, we need to ask whether we are using a tragedy/charity or medical model lens—and consider how our perceptions impact our interactions with disabled people and provision of their health care. In addition, nurse educators ought to provide opportunities for students to meaningfully engage with disabled people in both clinical settings and the classroom.

We also need to consider barriers to the inclusion of disabled nursing students that shape the processes used for admission to academic programs, provision of academic programs, and assignment to workplaces. Frain et al. (2007) reported that disabled nurses experienced stigma and a lack of acceptance in the workplace. Disabled nurses and physicians have reported having fewer career choices and opportunities for advancement compared to their non-disabled peers (Neal-Boylan et al., 2012). We should encourage nurse educators to reflect on the presence (or absence) of students with disabilities in their programs. Based upon human rights legislation in Canada, nursing schools cannot discriminate against students based upon disability. It is, therefore, the responsibility of nursing programs to facilitate inclusion of disabled people by providing appropriate and necessary accommodations. Nurse educators have a central role in identifying and addressing ableism in nursing, beginning with educational practices. The video *What’s Disability to Me? Rachael’s Story* features a powerful message from the perspective of a disabled nurse (WHO, 2011).

**Nursing Practice**

Nurses in practice also need to have an understanding of the implications of ethno-cultural assumptions regarding disability when caring for patients, families, and communities. As we have articulated in this chapter, discrimination and stigma within health care are commonly experienced by disabled people, particularly those with IDD (Pelleboer-Gunnink et al., 2017; Walsh et al., 2020). Further, discrimination and stigma experienced by disabled people can be exacerbated by race and ethnicity (Krahn et al., 2006; Magaña et al., 2012).
One particular area in nursing practice that needs improvement is access to services. Access issues may include physical barriers in buildings, as well as organizational barriers, such as inflexible policies and procedures (Bailey et al., 2019). Barriers caused by low incomes in the face of high costs of health services, equipment, and therapies also need to be addressed (Karpur et al., 2019; Raymaker et al., 2017).

Another area of nursing practice requiring attention is communication. Poor communication between disabled people and HCPs is reported frequently (Baumbusch et al., 2014; Redley et al., 2019; Sharby et al., 2015). Communication problems can be related to a range of factors, including (a) lack of appropriate interpreters; (b) the patient’s use of communication techniques and devices that are unfamiliar to HCPs; (c) noisy and distracting environments; and (d) lack of time for interactions.

To begin to address these issues, one approach nurses should take is to use trauma-informed care practices (Center for Substance Abuse Treatment, 2014). By using this approach, nurses acknowledge the trauma many disabled people experience. Trauma-informed care is characterized by:

- realizing the prevalence of trauma;
- recognizing signs and symptoms of trauma exposure;
- responding by integrating this knowledge into practice, procedures, and policy; and
- resisting re-traumatization or replication of prior trauma dynamics. (Center for Substance Abuse Treatment, 2014)

Trauma-informed care can be taken up by nurses at the individual level and by leaders at the organizational level to create systems-level changes. Importantly, researchers have indicated that when nurses integrated trauma-informed care into their practice, they were less likely to re-traumatize individuals (Lewis et al., 2019).

**Nursing Leadership**

As nurse leaders plan health care services and develop policy, it is imperative that they use a disability-inclusive approach. A central tenet of this approach is ensuring active and meaningful involve-
ment of people with disabilities in all aspects of planning, implementing, and evaluating services and policies. It is also important to raise awareness of the rights and needs of disabled people among everyone on the health care team; that is, regulated health care professionals as well as other staff on the team. Finally, careful examination of accessibility as it relates to services and policies is key. As part of this accessibility, nurse leaders ought to consider additional social factors that may be influencing an individual’s experiences, such as gender, sexual orientation, race, class, and age.

**Conclusion**

In this chapter, we provided foundational content about disability, including definitions, models, and current terminology and language. Many nurses have not had access to this type of knowledge in their pre-licensure education, and in order to provide appropriate care for disabled people across the life course, it is imperative that nurses understand how disability has been viewed in Western society over time. The influences of the tragedy/charity model and the medical model continue to shape health care delivery. Disabled people experience many inequities in health care, from value judgments about their very existence to barriers to recommended health care services, such as cancer screening. Advanced practice nurses are ideally situated across diverse practice settings to provide leadership by challenging and helping to address these inequities. Working with disabled people, nurses can contribute to the transformation of the health and health care of this large and diverse population.

**QUESTIONS FOR REFLECTION**

1. *How can a disability lens be integrated into nursing education in order to foster a more equitable experience for disabled people?*

2. *What are the implications of the medical model of disability and the social model of disability for the delivery of health care?*

3. *In your experience, what evidence is there of negative attitudes and biases against people with IDD in hospital care? How can these be addressed?*
4. How can the inclusion of disabled people in public health screening programs be increased?

5. What strategies can advanced practice nurse leaders implement to create disability-inclusive health care systems?
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“The COVID-19 pandemic shone a light on the significant gaps in the long-term care (LTC) system as never before. COVID-19 has precipitated, in the worst circumstances, high levels of physical, mental, and emotional suffering for our older adults. Those unnecessarily lost lives had value. Those older adults deserved a good closing phase of their lives and a good death…. We broke the covenant.” (Estabrooks et al., 2020, p. 9)
CANADA’S POPULATION DEMOGRAPHIC has changed dramatically since the 1950s. With declining fertility rates, declining mortality rates, and gains in life expectancy, the proportion of seniors over 65 years old (17.5%) now exceeds the proportion of children younger than 15 years old (16.0%).¹ For the first time in our history, seniors in Canada are projected to reach close to one-fourth of the overall population by 2040 (Public Health Agency of Canada [PHAC], 2020).

Seniors are a highly diverse group with differences in values, education levels, and socio-economic status. Within this heterogeneous group there are further differences, depending on whether seniors are over 65, 75, or 85. The average 65-year-old Canadian can expect to live an additional 21 years—and most experience overall good health. Related demographics include the following:

- The oldest group of seniors, those over 80 years, is growing rapidly and represents an increasing share of the senior population. The number of centenarians reached over 10,000 in 2019, with women accounting for 82% of those aged 100 years and over.
- Most Canadian seniors (92.1%) live in private dwellings in the community. Their desire for independent living requires an increased focus on health care and social services designed to support prevention of illness and health promotion.
- Approximately 7.9% of seniors live in residential care, such as residences for seniors or health care and related facilities. This group of older adults has complex health care needs, arising from chronic illnesses and, for many, dementia (Canadian Institute for Health Information [CIHI], 2018).
- Dementia, a neurocognitive disorder, is not a normal part of aging, but the likelihood of developing dementia increases with age. With its progressive trajectory, dementia directly affects many Canadians. Currently, over 500,000 people are living with dementia, and by 2030 the number is projected to almost double. In addition, one in five Canadians has experience caring for someone living with dementia (Alzheimer Society of Canada, 2021).

In this chapter, we provide a summary of the health and illness challenges older adults face, the relationship of these health and ill-
ness challenges to the social determinants of health, the pervasive impact of ageism, and the current systems of care available to address these challenges. An ethical critique, including application of the values of social justice and equity, will be provided to examine the devastation COVID-19 has brought to older adults living within institutional care facilities, as well as their families. We explore the complexities of developing a coordinated approach to long-term care (LTC) in Canada, along with a broader system of home and community-based health services for seniors. Further, the values underpinning a number of government and expert reports are discussed throughout. In our ethics critique, we explore the impact for persons living with dementia (approximately two-thirds of residents in LTC) (CIHI, 2020) and their family caregivers.

A Fragmented System

Societal attention to the quality of care available to older adults has increased dramatically as a result of the COVID-19 crisis. The media have continued to report extensively throughout the pandemic, exposing the dire situations and excessive deaths in LTC across Canada (Action for Reform of Residential Care BC [ARRCBC], 2021). Approximately 80% of COVID-19 related deaths during 2020 occurred among adults aged 65 years and older. Advanced age and underlying chronic diseases and conditions contributed to these severe outcomes (PHAC, 2021, p. 1). Between March 1, 2020, and February 15, 2021, more than 2,500 care homes across the country experienced a COVID-19 outbreak, resulting in the deaths of over 14,000 residents (CIHI, 2021, p. 6). The large number of deaths in LTC homes created a shock wave that cracked wide the many long-standing fractures in LTC operations.

Inadequate conditions in LTC have been recognized for decades, but this recognition has historically not translated into action. The system has been described as fragmented, patchwork, under-resourced, and heavily reliant on for-profit delivery (Armstrong & Cohen, 2020, p. 1), stemming from “blinkered policy choices forged by history” (Picard, 2020, para. 13). Expert authors of numerous values-based reports have provided resonating calls for action, while challenging society to make changes to culture, practice,
funding models, and policy within LTC and for older adults in general (Estabrooks et al., 2020; MacCourt et al., 2020; Office of the Seniors Advocate British Columbia, 2020a; Picard, 2021). In this chapter, we explore these calls for action and advocate for an ethical framework to support policy changes. Such a framework is crucial, as those calling for these actions ultimately aim to address human rights, dignity, safety, and respect for older adults in an environment where care providers embrace a holistic approach to care and a focus on overall quality of life.

The pandemic also exposed “fault lines” in the community, where the vast majority of older adults reside. Health care and inequity issues became more visible, reinforcing long-recognized gaps. For example, family members of older adults in the community have been struggling to meet their needs without support (Office of the Seniors Advocate British Columbia, 2018). Filling older adults’ care needs is necessary to counter isolation and promote well-being, and requires that home care resources are provided to help seniors to remain independent and safe in their homes. An integrated health care system must include foci on health promotion and mental health support, including for individuals living with dementia and their caregivers (Mental Health Commission of Canada, 2021).

The benefits of an integrated health care system were originally discussed, and recommendations made, in The Royal Commission on Health Care, Building on Values: The Future of Health Care in Canada (Romanow, 2002). Commissioner Romanow, who led this Royal Commission, emphasized that health care is a “moral enterprise, not a business venture” (p. xx). Governments allocate resources and, in so doing, express some common consensus about values (Holstein et al., 2011, p. 103). A foundational and relevant question pertinent to both policy and ethics has been proposed as, “What is the good, and how do we create, protect, cultivate it?” (Kenny & Giacomini, 2005, p. 247). People involved in policy and ethics should share a central commitment regarding what values they ought to embrace. These choices also tell a story about people and what is important to them (Kenny, 2002).
A New Vision: Healthy Aging

Many sources provide significant evidence that older adults can live longer, healthier lives by maintaining social connections, increasing physical activity, eating nutritiously, minimizing their risk for falls, and avoiding smoking. However, many older adults face inequities as well as environmental, systemic, and social barriers—including cultural factors, ability, income, and ageism—for adopting healthy behaviours. The Healthy Aging and Wellness Working Group (2006), in their report entitled Healthy Aging in Canada: A New Vision, A Vital Investment from Evidence to Action, recommends three key mechanisms to pursue a new vision for the promotion of healthy aging:

1. Supportive environments: developing policies, services, programs, and surroundings that support healthy aging across all settings.
2. Mutual aid: people supporting each other emotionally and physically, and sharing resources, ideas, information, and experiences.

Particularly salient is the United Nations (UN) and the World Health Organization (WHO) report entitled Decade of Healthy Ageing 2021-2030, which provides a comprehensive framework for change and a plan for action to combat the global issue of ageism. Key areas described in the framework include the design of age-friendly environments, the need for integrated care, and the need for support for quality of life in LTC settings (WHO, 2020a).

Ethical Leadership

Using ethics as a source of critical consciousness, advanced practice nurses and all health care leaders can raise questions about unexamined norms that are damaging or potentially threatening. Ethical leadership is vital to move forward and to participate in the clarion calls for action for the benefit of older adults. The language of ethics, such as values, rights, and norms, offers us a way to frame
our narrative about what outcomes we seek for those living in LTC environments and for those in the community. The expert and respectful care of older adults involves complexities with multiple layers. Thus, there is a need for comprehensive and integrated community and institutional health care resources for older adults, with more accountability demanded of health care planners and leaders. This invokes a range of implications for ethical leadership in health care delivery for older adults. A prerequisite for fostering this ethical leadership is a need to better understand and address societal attitudes toward aging.

**Attitudes Toward Aging**

Aging is a highly individualized and complex process, yet it continues to be stereotyped, especially in Western cultures. Myths and prejudices regarding aging abound in our present Western society, fuelling misunderstandings about older adults. Such misunderstandings set older adults apart, based on supposed characteristic qualities, even though older adults comprise the most diverse and individualized age group in the population (Miller, 2012, p. 5). In what follows, we explore current background conditions and messages that shape public attitudes, public policy, and the context-based choices that we make.

The term “ageism” was coined by the American physician Robert N. Butler, who contended that old age is equated by society with powerlessness, as a result of disease, disability, or uselessness (1989, p. 138). Ageism results in prejudices and stereotypes that are applied on the basis of age only, which leads to older adults being treated with a lack of dignity and respect, including a belief that they should not be given equal opportunities. Lindemann (2009) described this as a negative “master narrative” of aging that damages identity and oppresses the older adult group. Critics have also noted that those with a Western world view dominated by post-Enlightenment rationalism and economic productivity are prone to negatively adjust evaluation of the worth of any human being (Post, 2000; Taylor, 1989).

As a human rights violation, the scope and breadth of ageism is immense, including health care rationing on the basis of age.
Ageism can be associated with increased social isolation, decreased physical and mental health, and premature death (WHO, 2021). Ageist attitudes infiltrate all aspects of society, with discrimination institutionalized in public policies, such as mandatory retirement at specific ages.

The public’s responses to the COVID-19 pandemic have further exacerbated ageism and exposed inequalities of certain socio-demographic factors (Mikton et al., 2021; Sorrell, 2021). For example, those living in rural or deprived areas, or persons without social support, may face additional challenges. As is discussed later in this chapter, during the pandemic those living in LTC and other congregate settings have been more exposed to risks of contagion. A lack of resources and personal protective equipment (PPE) have compounded these issues (Ayalon et al., 2021).

Ageism is an issue globally, and the COVID-19 pandemic has highlighted the seriousness of existing gaps in policies, systems, and services. Action on healthy aging is urgently needed to ensure that older people can fulfill their potential with dignity and equality (WHO, 2020a), because ageism has serious and far-reaching consequences for people’s health and well-being, as well as human rights. Older people require access to all types of preventive and curative care while ensuring that use of these services does not cause them financial hardship; and that access to good-quality long-term care is essential to ensure people can enjoy basic human rights and live with dignity. The questions below offer opportunities for readers to reflect on issues about ageism.

**REFLECTIVE QUESTIONS**

1. **Has an older adult in your life talked about experiencing ageism? How did this impact their health or well-being?**

2. **In what ways do present-day societal views influence the attitudes of health care providers toward the care of seniors?**

3. **As a leader, what can you do to change the narrative around age and aging when communicating with other health care providers and policy-makers?**
The Trajectories of Aging and the Social Determinants of Health

Over time, definitions of healthy aging have evolved from focusing primarily on biological conditions to ones that optimize well-being. The World Health Organization takes a comprehensive view wherein health is seen as a positive resource for everyday living for all as they age. This view includes those in need of care, and defines healthy aging as “the process of developing and maintaining the functional ability that enables wellbeing in older age” (WHO, 2020a, para. 3).

Transitions and trajectories of aging are influenced by biological, medical, psychological, social, spiritual, and political factors. The Public Health Agency of Canada has identified 12 determinants of health (Government of Canada, 2020). For most older adults, daily life continues in advanced age with purpose and reaffirming activities. Unfortunately, for others this is not the case, and old age brings threats to personhood, including social isolation, loneliness, chronic illnesses, pain, dementia, stigmatizing labels and language, and institutional models of residential care. Social devaluation threatens dignity at an individual’s most fundamental level, and the effects of chronic illness and social devaluation that accompany frailty and inactivity threaten self-respect (Holstein et al., 2011, p. 11). Both self-respect and “horizons of meaning” (Taylor, 1989, p. 27) are essential and ground dignity.

Researchers have shown that well-being for older people is strongly related to functional independence status. Well-being is also affected by social determinants of health, including income and social status, social support networks, and education (WHO, 2020b). Focusing on well-being from a vantage point of the older adult’s health, including their strengths, capabilities, and resilience, is valuable for their care (Jett et al., 2012, p. 6). Further, the promotion of healthier older populations has significant consequences for health care and social/community support systems. Population aging, therefore, has important and far-reaching implications for nurse leaders working in all aspects of seniors’ health care, including education, research, practice, and policy.
Long-Term Care and Retirement Home Settings

As noted by a team of expert researchers, “Canada’s LTC sector has its roots in the Elizabethan Poor Law of 1601, not in the healthcare system. Provincial and territorial plans are disparate and piecemeal. The Canada Health Act does not protect or ensure universal LTC” (Estabrooks et al., 2020, p. 5). Further, there is no consistency in the structure and operation of LTC facilities across Canada, and there are both public and privately funded facilities. The different types of care facilities across Canada include

- LTC homes (also known as residential care or nursing homes) and complex care facilities provide 24-hour care, seven days a week. The majority of residents in these facilities have complex health care needs. LTC homes are funded or subsidized by provincial or territorial governments.

- Retirement homes, which are also known as assisted living, supportive living, and seniors’ villages, do not necessarily provide 24-hour care. These retirement homes do not receive public funding, and seniors and/or their families typically have to pay (except in some provinces) for the provision of assisted-living services.

- Mixed settings provide a mix of LTC and retirement home services for older Canadians and receive public funding (CIHI, 2021, p. 5).

In the next section, we describe how the long-standing fragmented situation in LTC in Canada has been revealed—and greatly exacerbated—by COVID-19.

Shining the Light on the COVID-19 Crisis in Long-Term Care

Canadian journalist André Picard (2021) discussed the COVID-19 crisis and how it exposed the neglect of elders:
As the pandemic swept around the world, it shone a spotlight on many existing social woes, not the least of which was how our elders have been neglected and forgotten. The crisis also exposed a tragic reality: the generation that had given Canada its beloved medicare system had clearly been forsaken by it. (p. 10)

From the first COVID-19 outbreak in a British Columbia LTC home to the disease’s devastating impact in Ontario and Quebec, Canadians have been shocked by a cascade of deaths and illness in LTC homes. In the first eight months of the COVID-19 pandemic, more than 80% of COVID-19 deaths occurred in LTC facilities (Statistics Canada, 2021, p. 1).

During this time, Canada experienced a far higher proportion of COVID-19 deaths in nursing homes than other comparable G20 countries—81% in Canada, compared to 28% in Australia, 31% in the US, and 66% in Spain (CIHI, 2020, p. 2). A year later, Canada still had, at 62%, the highest proportion of deaths in LTC of any G20 country. Of note, Canada spends about 30% less on LTC on average compared to other Organization for Economic Cooperation and Development (OECD) countries (National Institute on Ageing [NIA], 2020).

Mental disorders, including dementia, depression, and anxiety, are common in LTC. Despite the high need for mental health supports among LTC residents, their access to mental health care was poor even prior to the pandemic (Canadian Academy for Geriatric Psychiatry & Canadian Coalition for Seniors’ Mental Health, 2021, p. 1). As health care experts noted, “psychosocial, mental health, and emotional needs, as well as factors that promote well-being and quality of life, have been largely ignored as staff struggle to provide even basic physical care compassionately, and as residents languish” (MacCourt, 2021, p. 6).

The prime causes of the LTC crisis were summarized by Flood and colleagues (2021) as follows: Governments prioritized infection control in hospitals, returning infected patients to LTC homes and triggering outbreaks. In addition, there was a failure to provide LTC facilities with adequate PPE and to enforce infection control measures. Insufficient testing and tracing of staff, some of whom travelled between LTC facilities, was also a problem.
Over 20 international researchers in the field of aging discussed how older people are misrepresented and undervalued in the current public discourse surrounding the pandemic (Fraser et al., 2020). Ageism has been reflected in the lack of preparation for a crisis in LTC homes. There was, at the same time, an initial perception by the public that the virus was really an older adults’ problem.

During a public health crisis, administrative decision making is time pressured. Choices are made based on key principles of harm reduction and curtailment of deaths, with interventions deployed to reduce the spread of disease and mitigate its impact (Yeo et al., 2020). These interventions, however, can also result in an unintended cascade of negative outcomes. For example, visitation restrictions in LTC have resulted in serious repercussions for residents and their families, and families have voiced concerns throughout the pandemic. In British Columbia, a report from the Office of the Seniors Advocate of British Columbia (2020b) identified negative impacts on the health of LTC residents, including decreased physical and cognitive function and impaired mood and behaviour (p. 11). In the report from the Seniors Advocate, recommendations were provided for improved visitation measures that residents and family members believed were reasonable and that incorporated values related to quality of life and relationships in later years.

**The Broken Covenant Exposed**

The media, expert reports, investigations, and commissions have been instrumental in publicizing the LTC crises in Canada and exposing the broken covenant. Gaps in values and ethical actions point to resource and policy challenges in the system that are further illustrated by the following two examples. The first is the *Ontario LTC COVID-19 Commission Report*:

The report is grounded in the death and devastation that has marked Ontario’s long-term care homes during the COVID-19 pandemic. It serves to bear witness to the tragedy experienced by residents, families, and staff and to uncover
the factors that contributed to this shameful period in Ontario’s history. (Marrocco et al., 2021, p. 29)

The second example gives details about an investigation undertaken by the Quebec Ministry of Health and Social Services into one of Quebec’s hardest-hit LTC homes. Their report concluded that the facility suffered from “organizational negligence.” In the report, it was claimed that if management at the private seniors’ home had understood its responsibilities and used the resources at its disposal, the situation would have been less dire (CBC News, 2020, para. 18).

Voices From Canadians During the Pandemic

The following three narratives highlight the lived experience of LTC staff and family members during COVID-19. Their stories were documented in the 2020 report Honouring the Voices and Experiences of Long-Term Care Home Residents, Caregivers and Staff During the First Wave of COVID-19 in Ontario, by the Patient Ombudsman in Ontario.

ETHICS IN PRACTICE 15-1

**A Staff Member Reports Inadequate Resources**

A staff member contacted the Patient Ombudsman to share multiple concerns about the LTC home where she worked. She reported that prior to early April, 2020, PPE was not available. Once PPE became available, it was kept locked up by management. Ultimately, a majority of staff did not report to work as a result of illness or fear of infection. The remaining staff worked 15- to 18-hour shifts and were exhausted. There was no time to contact residents’ families to share information, and families were not receiving notification when a resident tested positive for COVID-19. Some replacement staff were hired, but they did not have health care experience and had not received infection prevention and control training. Residents did not have phones, so could not connect with their families, and many appeared depressed. Staff, including managers, were not wearing PPE correctly, and some were going from room to room without masks. When the LTC home staff member raised concerns about this practice, they were told that someone would be coming in to provide training in the next week. Residential staff were
later informed that local hospital staff had visited the home to review the situation and had not identified any problems (Patient Ombudsman, 2020, p. 16).

**REFLECTIVE QUESTIONS**

1. *Can you identify the internal moral distress and ethical conflicts of staff working in the situation above?*

2. *“Moral courage” encourages health care professionals to take action when doing the right thing is difficult. What is the significance of the courage of this staff member in deciding to contact the Patient Ombudsman?*

3. *In what manner was this staff member’s actions congruent with those of a whistleblower?*

You may find the following quote pertinent to your reflections: “Unless some people see injustices and oppression that others deny, there will be no impetus for change” (Myers, 1997, p. 25, cited in Holstein et al., 2011, p. 77).

**ETHICS IN PRACTICE 15-2**

**A Family Member’s Concerns About Inadequate Nutrition**

A family member contacted the Patient Ombudsman to express concern about her mother-in-law’s significant weight loss over the past month in a long-term care home. When the complainant was finally able to speak directly to a care provider in the home, she learned that her mother-in-law was eating only a small portion of her meals. Prior to the COVID-19 outbreak, her mother-in-law had received assistance with eating. Now there was no guaranteed assistance with eating after the food tray was delivered. The complainant’s mother-in-law did not have COVID-19, but many other residents of the home were ill or had died. The complainant expressed concern that residents were not just dying from COVID-19, but were experiencing varying levels of neglect, dehydration, and starvation as a result of staffing shortages (Patient Ombudsman, 2020, p. 18).
A Daughter’s Concerns for Loss of Support for Mother With Dementia

The complainant contacted the Patient Ombudsman to express concern about her inability to visit her mother in the long-term care home. The daughter reported that she played a significant role in providing stimulation and emotional support to her mother, who suffered from dementia. The daughter had asked to be considered an essential visitor, but was declined a visit with her mother because she did not feed or provide personal care to her mother. “I believe I am a support care partner that my mother needs and relies on to keep her feeling safe in her world,” the daughter wrote. “My Mom was all about family and having that support being taken away from her is devastating” (Patient Ombudsman, 2020, p. 15).

REFLECTIVE QUESTIONS

1. Do you think the definition of caregiving in this scenario should have been expanded? Provide a rationale for your response.

2. In future outbreaks, how could family visitation policies be made more flexible while preserving the safety of residents, families, and staff?

3. What impact do you believe visits from family caregivers would have had on persons living with dementia during this pandemic?
Consequences of Inaction and the Significant Need for Reform

As the elderly are not highly valued in the dominant culture, their care is believed to be primarily their own responsibility or the responsibility of their relatives and friends. Hospital and acute clinical care are valued more highly by society than either long-term care or the social care that is central to it (Armstrong, 2021). For several decades, there has been a growing recognition that Canada’s LTC system is in need of redesign (Estabrooks et al., 2020). The 2020–2021 media exposés across the country revealed stories of shocking neglect and mistreatment, raising questions about institutional care and recognizing an increase in acuity of health care needs among seniors who have no alternative but LTC (CIHI, 2020). As Baylis et al. (2008) noted, “A commitment to social justice requires us to recognize the special disadvantages that face members of social groups who are subject to systematic discrimination and reduced power” (p. 204).

The LTC sector is in a more obvious crisis now because of the severe impact of the COVID-19 pandemic on industry deficiencies. These deficiencies are the result of past failures by industry leaders to acknowledge the significant population trends in aging, such as the inequities faced by older Canadians living in poverty. The outcomes for LTC include inadequate structures and resources to ensure basic human rights, dignity, and quality of care for residents, and a lack of high-quality work environments for staff (Estabrooks et al., 2020). The LTC crisis has been further exacerbated by the scarcity of home care and the lack of funding for this care.

Priorities Moving Forward

Fortunately, a knowledge base has been building to promote insightful and integrated solutions for the major challenges in the LTC sector (Estabrooks et al., 2020; MacCourt et al., 2020). Priorities have been recommended by a number of policy experts; at the top of the list is the reform and redesign of the workforce. The goals are: (a) providing immediate benefits to improve the quality of care for older Canadians; (b) reducing unnecessary transfers to hospitals;
(c) reducing workforce injury claims; and (d) interfacing more effectively with home and community care (Estabrooks et al., 2020).

It is clear that there is an urgent need for new federal and provincial funds to undertake resolution of the LTC workforce crisis. Another key priority is the development of national standards for LTC commissioned by the federal government. A comprehensive, pan-Canadian, data-based assessment of national standards is therefore necessary. Care teams in nursing homes must have sufficient staffing numbers and a staffing mix to deliver quality care. These improvements should be promoted by tying new federal dollars to the national standards (Health Standards Organization [HSO], 2021). System reform should also integrate home and community care support for elders and family caregivers (Office of the Seniors Advocate British Columbia, 2018).

Consideration of the ethical dimension of policymaking is often sidelined by economic or political concerns, and this is nowhere more salient than in the care of older adults, particularly in the employment structure of LTC. Staffing practices require significant change, including increased recruitment and retention in all areas—nurse leaders, registered nurses, care aides, and other team members—to meet complex health and social care needs. These personnel must be both adequately trained and adequately compensated. Estabrooks et al. (2020) describe some of the weaknesses in Canada’s current LTC workforce:

The workforce mix in Canada’s nursing homes has changed, but has not evolved to align with the needs of older adults who need complex health and social care. Hands-on care is now almost entirely given by unregulated workers—care aides and personal support workers. They receive the lowest wages in the healthcare sector, are given variable and minimal formal training in LTC, and are rarely part of decision-making about care for residents. (p. 1)

Because trust has been lost, trust for all involved in LTC needs to be rebuilt. A relational ethical approach will be foundational to success in developing an ethical policy (Baylis et al., 2008). We need to focus on and attend to those who have lost their voices—the
vulnerable and marginalized—including those older adults lacking social and economic power. The NIA and the Canadian Medical Association (CMA) found in a survey that the vast majority of Canadians (86% overall and 97% of those over 65) were concerned about the state of LTC (NIA, 2021, p. 6). Based on these findings, the Canadian public may be ready to help to support such a focus.

Moving Forward: Activating the Consensus for Needed Changes

“A shift to a philosophy … that focuses on holistic care and quality of life, with physical/clinical care as background, is paramount and will enable residents to live their best possible lives, rather than simply existing” (MacCourt, 2021, p. 5). The key to continued well-being is the ability to live in environments that support and maintain a person’s intrinsic capacities and functions. This has profound implications for the design of care and living resources for older adults. Using such resources, policymakers and health care providers can better support a holistic approach to care and overall quality of life, supporting the rights, dignity, safety, and respect for older persons within their environment, whether they live in LTC or the community.

Ethical leadership is vital to envision and move needed change forward, to assert that older adults “should be able to live as fully integrated into their communities as their physical and cognitive capacities allow” (Holstein et al., 2011, p. 106). Using ethics as a source of critical consciousness, advanced practice nurse leaders can raise questions about unexamined norms, institutional shortcomings, and ageist views. In the Ethics in Practice scenario that follows, an advanced practice nurse leader is called upon to support an older adult with home care challenges after a fall.
A Fall, a Fracture, and Home Care Challenges

Mrs. S. was an 82-year-old woman who lived alone and took pride in her independence. She enjoyed life in her rented “cozy little apartment,” as she described it, in a small rural Alberta community, where she had lived for the past 30 years. Her husband had died of cancer several years earlier. She had no children but enjoyed a close relationship with a niece who lived in the same town, and she benefited from a sense of community with her friends and church. Mrs. S. walked regularly and visited with friends for coffee. During COVID-19, she and a good friend were in a “safe bubble.” She drove her car, a “little red jalopy,” weekly for groceries. She described herself as “healthy for my age,” but noted her vision was declining slowly, and she was taking a prescription for glaucoma. Her primary physician had retired two years earlier and since then, she had attended a local walk-in medical clinic when she needed a prescription refill.

One afternoon, Mrs. S. suffered a serious fall on her way to visit a friend. She was transported by ambulance to a local acute care hospital and was diagnosed with a fractured right arm and a mild concussion. She was admitted to the orthopedic ward for stabilization of her fracture and observation of her head injury. A rehabilitation assessment was not conducted because of staffing shortages in the hospital related to COVID-19. During her hospitalization, nursing staff expressed doubts about her ability to cope if she was discharged home. Nonetheless, Mrs. S. was insistent on returning home and adamant that she could manage with some support.

Because of her injuries, Mrs. S. was not able to drive her car. A discharge planning meeting was arranged, which included Mrs. S., her close friend, and her niece, as well as a home care nurse coordinator from the community.

REFLECTIVE QUESTIONS

As an advanced practice nurse in the community, consider these questions:

1. To plan the agenda, what further information is needed to support development of an action plan for Mrs. S.?

2. How may/will community support be a factor?

3. What resources would need to be in place to support Mrs. S.?

4. What ethical questions are a part of these discussions?

5. How can the care providers develop a care plan that supports Mrs. S.’s quality of life and recognizes the importance of her autonomy and resilience?
Cultural Change and Person-Centred Care in Long-Term Care

The COVID-19 crisis has revealed the need for a far-reaching cultural change in LTC. Culture change involves a move toward care that is person-centred; that honours the personhood of the elder. This culture change movement began with the pioneering work of gerontological visionaries Tom Kitwood in the 1980s (1997) and William Thomas (1994), who created the Eden Alternative model of elder support in the 1990s. Practitioners of this philosophy focus on the care of the human spirit as well as the human body within a “home” where elders direct their lives and experience well-being. Many models building on this early work have emerged over the years.

A Canadian example of a successful Eden Alternative-inspired program is found at the Sherbrooke Community Centre in Saskatoon, Saskatchewan. Adopted in 1999, the program guides staff to “[support] each person to live a full and abundant life, creating a diverse habitat where children, plants, and animals are a natural part of everyday life” (Sherbrooke Community Centre, n.d., heading 1). Further, Sherbrooke leaders are prolific authors, teachers, and speakers on behalf of this respectful approach to elder care. A second example, the Butterfly Approach for dementia care, was recently adopted by The Sunnyside Home in Kitchener, Ontario. The Butterfly Approach is described as “essentially reshape[ing] the care home into more of a shared household rather than a facility” (Pace, 2021, para. 5).

Promotion and acceptance of this person-centred culture change continues to evolve. A special edition of HealthcarePapers’ New Models for New Healthcare (2021) included recent work on

6. What policy changes are needed at local and provincial levels to support the needs of Mrs. S. and others in similar situations? Include a focus on prevention as well as treatment and rehabilitation.

* For more information about home care, please see Chapter 13 in this textbook.
models designed to transform LTC into a person-centred environment where vulnerable people are safe and receive the care they need. These models could ensure that the health care system provides community services that support older adults to live in the community longer, safely and independently (Laporte & Siddiqi, 2021, p. 7). In these models, different but related aspects of LTC were emphasized, including personal care, regulatory standards, and physical and staff environments.

Morton-Chang and Williams (2021) recommended an integrated community-based continuum of care. As for the care environment, August (2021) noted that for-profit LTC experienced higher resident death rates; therefore, August called for radical change for elimination of the profit motive. Drummond and Sinclair (2021) argued that home and community-based support should replace institutionalization of the elderly.

Turning to the regulatory environment, Tuohy (2021) suggested that the federal and provincial governments work collaboratively to develop an LTC insurance program, while Flood et al. (2021) argued for development of a federal-provincial governance framework administered by independent experts to ensure the quality, safety, and timeliness of LTC services.

Berta and Dawson (2021) highlighted the critical role physical and work designs—the “built environment”—play in promoting and sustaining health. They called for designs informed by knowledge of pathogenesis; that is, consideration of factors that might influence the development of an infection into a more serious issue for the individual affected or their community. Further, Estabrooks (2021) noted the need for consensus on staffing requirements for LTC, while Fancott et al. (2021) emphasized the importance of placing caregivers at the heart of LTC delivery to ensure balanced policies in person-centred care.

**Leading Ethical Policy Change: Ethical Framing**

An ethical framing gives us normative direction regarding the “oughts” of health care delivery. More specifically, an ethical framing helps us to analyze what is happening in
health care delivery, what ought to happen, and how to navigate the difference in health care practice and policy. (Rodney et al., cited in MacCourt et al., 2020, p. 67)

It is clear from the call-to-action reports discussed above that taking responsibility for the impacts of COVID-19 on seniors in LTC and in communities is complex. The reports from experts and advocates, and the stories the media have exposed, have acted as a catalyst for a new, ethically sensitive approach to policymaking, and have served as a crucial first step toward developing an ethically informed policy for person-centred care in LTC, as well as for the care of older adults in general.

All policy has an inherent normative ethical dimension, as it concerns how things ought to be—how we ought to behave; how we ought to treat one another. Yet, consideration of the ethical dimension of policymaking is often sidelined by economic or political concerns. It is therefore essential to ground policy in clear and consistent values. Baylis et al. (2008) proposed relational personhood and relational solidarity as core values for public health ethics, and noted that these values apply to diverse populations. As our analyses in this chapter have demonstrated, it is also essential to focus on the interplay among the various levels—federal, provincial, and local—of health care policymaking. Questions of accessibility require reflection and analysis. When decisions have a profound impact on the public, there should be deliberative public engagement processes for diverse individuals and communities to express their views and values on decisions made, and to have those decisions reviewed to prepare for the future. Transparency, explicitness, clear communication, and continuing education are central to ethical decisions.

Health care providers, leaders, and policymakers, therefore, need to change how policy is addressed. Through this change, they need to recognize the fundamentally ethical nature of policy, where ethics is not seen as an extraneous afterthought, but as an inexorable element of policy. Everyone needs to understand that ethics provides life and light to policy, and that an ethically robust policy is a policy with a human face.
This approach is especially important when developing policy for vulnerable populations such as older adults. To safeguard older adults, including those with dementia, the “connecting, synthesizing link is the morality of civic equality” (Harrigan & Gillett, 2009, p. 49). Decision makers need a nationally supported ethical framework to guide policy decisions made at provincial and health authority levels in relation to resource allocation and access to services and support for seniors in LTC, as well as those living in the community.

A consistent commitment to ethical framing guides health care leaders and providers from diverse caregiving and professional backgrounds to address value-laden practice and policy questions arising for all individuals in various care settings, including elder clients, residents, and family members. Further, ethical framing can help us to move more fully to a person-centred, relational approach. This is more important now than ever before. “The Coronavirus pandemic is shaking up the moral universe and puts profound philosophical questions to the test. It is a test of the ideas humans choose to help them form moral judgements and guide personal and social behaviors” (Authers, 2020, pp. 2–3).

**Conclusion**

Challenging the health care inequities for older adults in Canada is a moral imperative. The multitude of issues discussed in this chapter are amenable to resolution, and the solutions proposed have support from researchers, health care providers, older adults, residents in LTC, and family members. We can hear voices of optimism, such as those from groups of health care workers who believe that out of this humanitarian heartbreak “we have the potential to turn that tragedy into the kind of momentum that can fix the system for good” (Umaigba et al., 2021, para. 14). There is also a voice of hope from the BC Seniors Advocate, who noted that as well as observing pain and suffering, “we also witnessed tenacity, commitment, and opportunity to use what we have learned to improve long-term care” (Office of the Seniors Advocate British Columbia, 2021, p. 2).

Development of National Standards for LTC services in Canada are underway. The draft standards were completed and widely
circulated for response early in 2022. The voices of many Canadians were solicited in the process.\textsuperscript{9} The standards will promote the delivery of safe, reliable, and high-quality services, as well as infection prevention and control practices in LTC homes (HSO, 2021).

It will take resolve and political will to effect comprehensive system change for the care of older adults in LTC, as well as those living in the broader community. Advanced practice nurse leaders with expertise in ethics must lead the drive forward. An ethical framework must be confirmed as a key strategy for addressing complex problems, and an ethical lens must be consistently applied to planning and goal-setting discussions for families, communities, and institutions. We urge nurse leaders—individually and collectively—from their positions in practice, education, research, and policymaking, to participate in and contribute to solutions for quality care for older adults. The 1977 quote by Humphrey below is still applicable today.

The moral test of government is how it treats those who are in the dawn of life, the children; those who are in the twilight of life, the aged; and those in the shadows of life, the sick, the needy and the handicapped. (p. 37287)

**QUESTIONS FOR REFLECTION**

1. *How has this chapter broadened your understanding of the pervasiveness of ageism?*

2. *What are the ethical responsibilities of advanced practice nurse leaders in challenging the inequalities in older adult care in communities, homes, and institutions such as LTC?*

3. *What strategies might nurse leaders engage in for practice and policy change at micro, meso, and macro levels of the health care system?*

4. *What constraints or facilitators might advanced practice nurse leaders experience in taking action?*

5. *What are some strategies for public education and health promotion related to the care of older adults?*
Endnotes


2 Two websites of note are The Fountain of Health at www.fountainofhealth.ca/our-research and The Canadian Coalition for Seniors Mental Health at www.ccsmh.ca/ccsmh-national-guidelines-for-seniors-mental-health

3 The main determinants of health include income and social status, employment and working conditions, education and literacy, childhood experiences, physical environments, social supports and coping skills, healthy behaviours, access to health services, biology and genetic endowment, gender, culture and race/ethnicity. (Government of Canada, 2020).

4 Horizon of Meaning: A horizon is foundational, a background within which one determines what has meaning—“what is good or valuable. … In other words it is the horizon in which I am capable of taking a stand (Taylor, 1989, p. 27).

5 The Elizabethan Poor Law of 1601 (formally The Act for the Relief of the Poor) was an Act that governed distribution of relief for the poor. Because this law was administered at the parish level, there was considerable variation in the categories of poor people who were included and the kind of help they received.

6 “The pandemic claimed the lives of at least 7,000 elders living in nursing and retirement homes between March and August … Those living in these homes were 77 times more likely to die than their counterparts still living in homes and apartments” (Picard, 2020, para. 5).

7 For a list of media sources on COVID-19 and LTC, visit www.arrcbc.ca/medialist.pdf

8 See the National Institute for Aging and Canadian Medical Association’s survey at Pandemic Perspectives on Long-Term Care: Insights from Canadians in Light of COVID-19 (cma.ca).


References


Authers, J. (2020). How coronavirus is shaking up the moral universe: The pandemic is putting profound philosophical questions to the test. In M. Schwartz (Ed.), *The ethics of pandemics* (pp. 2–8). Broadview Press.


Imagine, for a moment, that you are dying. You are reaching the end of your own life, and you are experiencing the best death that you could have wished for. As you imagine this, ask yourself the following questions: Where are you and who is with you? What are you thinking and feeling? Are you awake or asleep? Are you comfortable? What do you hope for?

 Conjuring images of our own death might seem morbid, but exercises like this can encourage thoughtful reflections on what we value, for ourselves and those we care for, at the end of life. In this
chapter, we consider different places where death and dying occur in Canada, showing how each are imbued with important ethical considerations. We reflect on the nature of suffering in end-of-life care, and challenge readers to critically examine the ubiquitous assumption that the alleviation of suffering is invariably a moral good. We then introduce the notion of a palliative ethic, which provides guidance for nurses and other health care providers (HCPs) through end-of-life care by upholding two fundamental values: dignity and justice. Nurses in advanced practice leadership roles are in key positions to support such values. We offer analysis of two case studies, one about medical assistance in dying, and the other about equity in care. We finish the chapter by centring the perspectives of LGBTQ2 people who—like so many other marginalized groups—are often left out of end-of-life scholarship and practice. The questions above are useful to keep in mind while moving through this chapter, as we consider the heterogeneous landscapes of death and dying in Canadian health care, and the ways in which important nursing values are enacted (or undermined) across this terrain.

**Places for End-Of-Life Care**

Although acute care hospitals and long-term care residences are common places of dying in Canada, they are often ill-equipped to support a quality end-of-life experience. In a Canadian ethnography of an acute medicine unit in a large urban hospital, Chan et al. (2018) described a culture of busyness where the needs of dying people were de-prioritized. In this context, it was not the knowledge or skill of individual nurses that shaped end-of-life care, but rather “a systematic, taken-for-granted lack of importance granted to dying patients on the acute medical ward” (p. 462). Similar issues play out in long-term care. Wiersma and colleagues (2019) described how long-term care is characterized by a focus on time, tasks, and care of physical bodies, where “residents’ emotional and psychosocial needs can be ignored as the staff work is reduced to a series of tasks to be ticked off at the end of the shift” (p. 271).

When asked, many Canadians would prefer to die at home. But achieving a home death requires significant resources—particularly
unpaid family caregiving and skilled nursing support—which are often unavailable. As noted in interviews of bereaved people in Toronto (Mohammed et al., 2018), family caregivers in the home are often “thrust into a situation of needing to assume responsibility for crucial tasks” (p. 1234). They take on these responsibilities not because they want to, but because they are compelled to fill gaps created by the unavailability of professional palliative home care services.

Dedicated palliative care settings are another important location for end-of-life care. Here, nurses and other health care providers have expert knowledge about end-of-life issues, and are well-equipped to organize care around giving people their best chance at achieving the kind of death that they find meaningful, a “good death”—whatever that means for them. However, specialized palliative care settings are not a panacea for issues faced in dying, death, and grief. In contrast to the places described above, nursing care has a slower pace, and the fact that families are not overwhelmed with formal caregiving responsibilities means that distinct kinds of ethical questions rise to the surface. For example, should nurses turn and position an immobile patient who is close to death, whose bone pain makes it impossible to tolerate more than one specific position, and whose skin is breaking down? How should nurses approach the symptom management of a patient whose shortness of breath could be relieved by morphine, but whose family adamantly refuses it because of the symbolic associations they draw between opioids and death? Although some might find it tempting to locate an answer to such questions in a clinical, logical approach, this can obscure the human values at stake in these scenarios.

**Suffering in End-Of-Life Care**

Persons approaching end of life experience many types of suffering (Krikorian et al., 2012). The phenomenology of this suffering is often related to the inability to do meaningful things, a loss of dignity, and a change in one’s sense of personhood, particularly in relation to how others view them (Svenaeus, 2020). The goal of palliative care is to prevent and relieve such suffering (World Health Organization, 2020). But the irony of such a goal is that it may also
set up the expectation that one should not suffer at the end of life, an expectation that may be difficult to achieve in light of the multiple concurrent losses that persons experience as they approach death (Henry, 2017). While great progress has been made within palliative care in the suffering related to physical symptoms, the existential suffering that occurs as a result of these losses can be more difficult to treat.

Evidence-based treatment options for such existential suffering are few. “Dignity Therapy” (Dignity in Care, n.d.), in which people conduct a life review, has shown promising benefits for patients and their families (Martínez et al., 2017). Recently, there has been interest in the use of psychedelics for the treatment of existential and psychological suffering at the end of life. There is preliminary evidence to suggest that psychedelic-assisted therapy may induce mystical-like experiences that can improve mood and anxiety with lasting benefits (Rosenbaum et al., 2019). Palliative sedation is an established treatment for refractory symptoms: sedatives are used in proportions that alleviate a patient’s symptoms, even to the point of unconsciousness. However, there is ethical debate about whether palliative sedation should be used to treat existential suffering, or whether it should be reserved for physical symptoms such as breathlessness or restlessness (Rodrigues et al., 2018). This type of existential suffering often leads to medical assistance in dying (MAiD) as a treatment option. As reported in the Second Annual Report on Medical Assistance in Dying in Canada (Health Canada, 2020), the two most prevalent sufferings that led to a request for assisted death were the loss of ability to engage in meaningful activities (84.9%) and a loss of ability to perform activities of daily living (81.7%). Even for physical suffering, some people will place a higher moral value on being comfortable than being awake, while others will prefer to forego symptom relief so they can engage in important cognitive or spiritual work and meaning-making before death (Wright et al., 2020).

In considering these options for treating suffering, it is important for nurses to understand how world views (for example, values, beliefs, explanatory narratives) frame individuals’ perspectives of suffering. Suffering is always socially mediated, and can be framed on a continuum, from something that should be abolished, to some-
thing that has an inherent role in human growth and transformation (Aaltola, 2018; Beaman & Steele, 2018). In a spiritually and culturally diverse society, there will be various interpretations of the role and value of suffering in a good life and a good death.

The meaning that individuals assign to their death, and their beliefs about what comes after, are essential to consider as part of ethical end-of-life care. The Code of Ethics for Registered Nurses (Canadian Nurses Association [CNA], 2017) recognizes how important such beliefs are to human dignity: “In health-care decision-making, in treatment and in care, nurses work with persons receiving care to take into account their values, customs and spiritual beliefs, as well as their social and economic circumstances without judgment or bias” (p. 12). Ultimately, these beliefs provide patients and families an integrating framework for life and for death. Individuals use them to make sense of their being in the world and to guide their choices toward a moral good. In that sense, they can be a stabilizing force as persons receiving palliative care face the impending death of their physical bodies.

Cassell and Rich (2010) argue that a person is “an embodied, purposeful, thinking, feeling, emotional, reflective, relational human individual existing through time in a narrative sense” (p. 436). Suffering, according to these authors, occurs when there is disruption to the coherence or cohesiveness of that narrative whole. In a recent text that chronicled stories from the field of palliative care nursing, White (2022) highlighted the long-lasting ramifications of disrespecting deeply held desires in end-of-life care, including the desire to abstain from interventions meant to promote comfort. The author described a disruption to the narrative coherence of a bereaved spouse whose husband did not wish to receive medication before he died, when a nurse was unable to accept this choice.

In caring for her husband at the end of his life, she wanted to honor his wish not to receive medication through his transition between life and death. He had been a scholar of Advaita Vedanta and Eastern philosophies and he wanted a clear mind at the end of life. When her husband, in his dying hours, was appearing uncomfortable, the nurse encouraged [her] toward a decision to medicate. In the end,
she acquiesced at the constant insistence of the nurse who said that the amount of medication was very small, and her husband received medication. This decision stays with her to this day; it is one she still questions. (White, p. 29)

In reflecting on the choices available at the end of life, Farrow (2018) encourages us to pay attention to the “human vocation to immortality” in connecting the well-being of the body and soul. For those who, based on their faith commitments, embrace this vocation, a good death could include such commitments. This is just one of the many reasons why interdisciplinary approaches are critical for high-quality end-of-life care. Only an interdisciplinary approach, including contributions from experts in spiritual care, can provide the perspectives that are required for an ethical approach to human diversity. Advanced practice nurses are in key roles to promote such interdisciplinary collaboration.

A Palliative Care Ethic

Using a palliative approach as an overall ethic of care orients health care practitioners in articulating a philosophy of practice that centres certain values as fundamental in the care of dying people, their families, and their communities. Of course, seeking to articulate a unifying framework for ethical end-of-life care, based on core values, is a risky endeavour. In their now classic critique of the ideology of a “good death” for palliative care, Hart and colleagues (1998) highlighted the inherent normativity of this concept, which risks labelling certain modes of dying, and by extension the people who die in those ways, as morally inferior:

And so we have “good deaths” and “bad deaths,” and “good” and “bad” patients; these stereotypes recur within hospitals and hospice care. Sociological, psychological and nursing research has already demonstrated, through recurring themes in the literature, that “bad” patients are those who fail to conform, who deviate from normative behaviours and choices, and who fail to legitimate the roles of their caregivers. (p. 72)
Our challenge is thus to articulate an ethics for end-of-life care nursing that is both specific enough to focus on meaningful values, and also resists marginalizing the diverse interests and perspectives of those it purports to support. Although all of the values articulated in the 2017 CNA Code of Ethics are relevant to the ethics of end-of-life care, we suggest that two are particularly salient for the care of people facing death, dying, and grief: honouring dignity and promoting justice.

Next, we present and analyze two cases that, in different ways, surface ethical questions around how nurses can honour dignity and promote justice in their end-of-life care practice. In the first case, we discuss medical assistance in dying (MAiD). This topic is important in Canada, as the legislative landscape for end-of-life care continues to change, and nurses are challenged to care for patients in ways that may be unfamiliar to them. In the second case, we consider questions of equity in palliative care nursing. Taken together, the cases demonstrate an approach to analyzing the ethics of end-of-life care nursing, in diverse contexts, through reference to two fundamental questions: What is at stake for this person/family/community, at this time and in this place? And how do we best honour dignity and promote justice in this situation?

**Expanding Options: Medical Assistance in Dying (MAID)**

Canadians who meet the eligibility criteria defined in Bill c-7 (Parliament of Canada, 2021) have the option of ending their lives through MAiD. MAiD is the administration of medications to cause death either through oral self-administration, or through intravenous administration by a physician or nurse practitioner. Increasing numbers of persons are choosing this end-of-life option, particularly in BC and Ontario (Government of Canada, 2020). As of March 2021, MAiD is not restricted to those who are at the end of life. Rather, persons whose death is not reasonably foreseeable are also eligible for MAiD providing they meet certain criteria, as outlined in Bill c-7. As such, increasing numbers of nurses who work in diverse practice areas will be involved in caring for people requesting MAiD. Nurses will need to become familiar with end-of-life
practices as they seek to provide care for all those choosing MAID, including those who do not have a terminal diagnosis.

MAID generated significant moral debate in Canada. Public consultation in preparation for Bill C-7, the revision that allowed MAID for those persons whose death is not reasonably foreseeable, provided some indication of this debate (Government of Canada, 2020). Of the eight central themes generated from the 254,000 comments by Canadians, one was about ongoing opposition to MAID and one was about concerns related to expanding eligibility requirements. Preliminary evidence from nurses in Canada reflected the same range of moral response; nurses described a process of morally grappling with this new treatment option (Beuthin et al., 2018; Pesut, Thorne, Storch, et al., 2020; Wright et al., 2021). For some nurses, participation in MAID has been one of the most rewarding aspects of their career. These nurses characterized MAID as a beautiful death, and their involvement as life- and career-changing. In part, this is a result of the long legacy of nurses who bore witness to suffering with few options available to relieve it. However, for other nurses, the introduction of MAID into their working environments has been so morally difficult that they have chosen to change jobs or retire from nursing. When nurses are reluctant to be involved in MAID, the reasons are multi-faceted. For some, it may be related to a belief that it is morally wrong to hasten death. For others the reluctance may be related to the emotional labour and impact of participating in MAID; previous personal and professional experiences of suffering and end-of-life care; or feelings of incompetence related to MAID policies and procedures (Brown et al., 2021). Although a percentage of nurses have clear beliefs about whether they support or are opposed to MAID, there are many who describe themselves as being in a state of moral indecision; they are not sure what they believe about MAID, but they are open to learning and making a decision over time as they experience the MAID process (Pesut, Thorne, Storch, et al., 2020).

What unites nurses across these moral differences is agreement that the implementation of MAID has been emotionally impactful for all involved. Nurses have described their initial experiences with MAID with a sense of shock attended by a wide range of emotional responses (Pesut, Thorne, Storch, et al., 2020). Although the initial
shock typically wanes, the sense of gravity and profundity of the act does not.

The MAiD legislation, as well as professional and health-region standards, permits nurses to take a stand of conscientious objection to MAiD. In the case of conscientious objection, nurses are required to make a declaration to a supervisor well in advance of their potential involvement in a MAiD case, and supervisors are required to make accommodations. However, all nurses are still required to perform relevant responsibilities derived from the 2017 CNA Code of Ethics, such as non-abandonment, and there are limits on what nurses can conscientiously object to. For example, in many health regions nurses are only allowed to step back from participation in the actual administration of the medications, while being required to provide other aspects of care for persons and family.

Evidence from the experiences of nurses in the Canadian context indicates that being a conscientious objector can have negative consequences. Nurses may feel stigmatized or unsupported in their workplaces (Lamb et al., 2019; Pesut, Thorne, Schiller, et al., 2020) or worry about putting excessive burdens of care on their colleagues (Pesut, Thorne, & Greig, 2020). For example, in busy workplaces, nurses are aware that the forms of patient care they object to must be done by someone else, and working with patients and families considering or receiving MAiD can be difficult, emotional work. These concerns are particularly relevant for those nurses for whom MAiD has become a regular part of their employment responsibilities. For example, community care nurses who work with clients living with palliative needs in the home may find themselves developing long-term relationships with clients, and then handing over their care to another provider at the very time when those clients need them the most. In these situations, nurses experienced very real moral tensions when they believed they had no good options (Pesut, Thorne, Storch, et al., 2020).

It is important to note that conscientious objection is not the only reason that nurses choose not to be involved in MAiD. One of the most morally relevant reasons is that some nurses find themselves having psychological sequelae after participating in a number of medically assisted deaths. These nurses are not conscientious objectors; they agree with the right to an assisted death,
but they are no longer able to participate because of the emotional impact that involvement has had on their lives (Pesut, Thorne, Storch, et al., 2020). Nurses described this experience as ruminating excessively over medically assisted deaths to the point where it started to impact other aspects of their lives. Allowances for conscientious objection do not consider these other morally difficult situations, and so it is critical that nursing leaders recognize and provide options for nurses who find themselves in these situations.

We now turn to Ethics in Practice 16-1 to illustrate the conflicts an NP may feel when they are facing a MAID situation.

**ETHICS IN PRACTICE 16-1**  
“Suffering Unbearably”: Engaging With MAID Through a Relational Lens

Mona, a 45-year-old woman living on a disability pension, has struggled with severe rheumatoid arthritis and chronic pain for decades. She is becoming increasingly dependent upon others for her care and states that she is suffering unbearably. She has lived independently to this point but must soon seek a different living arrangement as she is no longer able to cope on her own. There are limited housing options available in her rural community, but she is unwilling to relocate from the community where she was born and where she raised her children. Her two children live at a distance but keep in regular contact with their mother by phone. Mona decides that she no longer wants to live this way, contacts the MAID coordination service, and requests assessment for MAID.

Mona’s children strongly object to this decision. They immediately fly out to convince Mona to withdraw her request. They have a number of concerns: they believe that their mother has many years of life left, and they are worried that she has become depressed because her symptoms have not been treated adequately. They are willing to relocate her to their own homes and ensure that she gets good treatment for her arthritis and pain. They worry that she is making a decision that is not in keeping with her long-held values.

Mark is the nurse practitioner assigned to do Mona’s assessment. Mark is the provider for a group of patients in the community living with advanced chronic illness and requiring palliative care. Mark decided to become involved in MAID in his rural community because there were no other assessors and providers willing to do the work. This involvement has come at a cost; some members of his rural community have disagreed with his decision and no longer seek his professional care. Mark feels
Assessing the Ethics of the Situation: Relationships, Goals, Beliefs, and Values

Persons often choose MAiD because they want choice over their lives and wish to maintain a sense of dignity. Many describe the moment of choosing to have a MAiD assessment as the line in the sand where the situation in which they find themselves makes death preferable to life as they endure ongoing suffering. Mona, it seems, has reached that point. The situation that she finds herself in because of pain and loss of independence means that she now wants to consider at least having the option of an assisted death. This is an important point. Requesting a MAiD assessment does not always mean that the individual is choosing to have a medically assisted death; rather, it becomes an option if their situation becomes unbearable. Nurses have described the change that they see in some persons once they have the option of MAiD; they become more relaxed, hopeful, and, in some cases, their symptoms diminish (Pesut, Thorne, Schiller, Greig, Roussel, et al., 2020). Having choices is therapeutic for many patients.

Mona’s relationships are also an important consideration. Her family is worried that Mona has been put in an untenable situation because of inadequate care, and that her choice is out of alignment with her long-held values. An important equity question in this conflicted about providing MAiD to Mona, whose death is not reasonably foreseeable, and he is not sure how to approach her assessment.

REFLECTIVE QUESTIONS

1. What equity issues are involved in this situation?
2. How might Mark decide whether this is a fully informed and authentic choice for Mona?
3. How should the opinions and needs of Mona’s children be addressed?
4. How should Mark be involved given that he is conflicted about MAiD when death is not reasonably foreseeable?
5. What is Mark’s duty of care in Mona’s situation?

Assessing the Ethics of the Situation: Relationships, Goals, Beliefs, and Values

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Mona’s relationships are also an important consideration. Her family is worried that Mona has been put in an untenable situation because of inadequate care, and that her choice is out of alignment with her long-held values. An important equity question in this
Ethics in Practice case is whether Mona has access to the care and living situations that would alleviate her suffering. Nurses are expected to “work with persons receiving care to explore the range of health-care choices available to them, recognizing that some have limited choices because of social, economic, geographic or other factors that lead to inequities” (CNA, 2017, p. 10). People living in rural areas of Canada often lack the same access to health care options and living arrangements that are available to persons living in urban areas (Wilson et al., 2020).

Furthermore, we need to learn whether this decision is in keeping with Mona's long-held values. NPs who perform MAiD assessments suggest that one of the most important indicators that they look for is whether this is a decision in keeping with who this person has been over time (Pesut, Wright, et al., 2021). Nurses should pay attention to what family members and significant others have to say on this topic. Those nurses who have been involved with MAiD over time suggest that working with the family unit to gain a deeper understanding is one of their most important interventions.

Finally, we come to Mark and his situation. With the change in law, it is now important for Mark to consider his own beliefs and values about MAiD. Mark has a number of difficult considerations: can he come to terms with providing MAiD to a person whose death is not reasonably foreseeable? If not, does he risk moral injury by agreeing to be involved? Early evidence from research with Canadian nurses has indicated that this is not an uncommon moral question (Pesut et al., 2021). How does Mark weigh the value of being involved in MAiD assessment and provision against his other responsibilities to care for persons in his rural community? Will more persons decline his care when they hear of his involvement? Rural NPs have indicated that this is one of the most concerning aspects of providing MAiD-related care in their communities (Pesut, Thorne, Storch, et al., 2020). Ultimately, Mark needs to balance his own beliefs and values, his relationships with those in his community, and his professional obligations as a health care provider.
Reflecting on and Reviewing Potential Actions

What are some nursing actions that can be taken in this complex situation? First, Mark can take time to hear Mona’s story of suffering to gain a deeper understanding of the situation, thus fulfilling the 2017 CNA Code of Ethics requirement to “work with persons receiving care to take into account their values, customs and spiritual beliefs as well as their social and economic circumstances without judgement or bias” (p. 12). NPs responsible for MAiD assessment need to include the illness trajectory of the patient, the circumstances surrounding their decision to apply for the assessment and what prompted it, and, importantly, how they thought about MAiD prior to this decision (Pesut, Wright, et al., 2021). For example, if Mona was opposed to MAiD, what factors influenced her to change her decision? Mark also needs to explore the degree to which the circumstances that have led to this suffering have been or can be addressed. Has Mona’s health care provider addressed her issues of pain? Does she know her options in terms of remaining independent? Is she aware of the possible living arrangements in her community?

Once Mark has gained a deeper understanding of the situation, he can request Mona’s permission to have a family conference. In doing so, he will be fulfilling the 2017 CNA Code of Ethics responsibilities to “respect the privacy of persons receiving care” (p. 12) while also seeking to “assist families in gaining an understanding of the person’s decisions” (p. 12). NPs who conduct these family conferences suggest that families are much better prepared to support decisions when they have the chance to hear the story of their family member’s suffering in detail (Pesut, Thorne, et al., 2020). Family, particularly those who live at a distance, may not be aware of the day-to-day suffering experienced by those living with illness. A request for MAiD assessment can also imply that family caregiving has been insufficient (Pesut, Wright, et al., 2021). If left unaddressed, such interpretations risk negative consequences as the family experiences grief after the person dies.

Mark can also spend some time reflecting on his own moral responses to the situation. The 2017 CNA Code of Ethics envisions a “moral community in which ethical values and challenges can be
openly discussed and supported” (p. 13). Nurses engaged in MAiD-related care indicate that discussing their choices about their involvement in MAiD with their family and colleagues is essential (Pesut, Thorne, Storch, et al., 2020). There is a cost, particularly for Mark, in being involved in MAiD, and it is important that the significant people in his personal life are supportive of him in this choice. Likewise, colleagues can help him understand their own moral reasoning related to their involvement and the subsequent impacts on their lives and practice. In this moral reflection, Mark can explore whether he should perform the assessment about MAiD but not the provision. This is an intermediate option if Mark wants to be available to support his patient, but cannot reconcile with providing assisted death himself.

Selecting an Ethical Action: Maximizing the Good

Mark decides that in this situation he needs to complete Mona’s assessment. As he hears her story of suffering, he feels deeply empathetic to her situation and agrees that she has met the criteria under the law, but cannot imagine himself providing MAiD for her. Many good outcomes are derived from the family conference: Mona’s children become proactive in advocating for more aggressive symptom management after they better understand what she has endured. Two assessors find Mona eligible for MAiD, but she decides not to proceed with the provision at this time; she is content to have the option available should she wish to proceed. Mark notifies the MAiD coordination service that in future he will only provide assessments and provisions to those clients who are already part of his primary care practice. The coordination service agrees to seek out other health care personnel who can fill the gap.

Nurses in diverse roles in Canada have provided leadership in regard to MAiD. Canadian NPs act as assessors for and providers of MAiD, and registered nurses, particularly advanced practice nurses, often lead interdisciplinary teams. The moral climate of the workplace is established by providing clear guidance for high quality patient and family care, establishing processes that allow nurses to choose whether to participate in MAiD in accordance with their conscience, and providing resources (for example, team support,
debriefing) to support nurses’ wellness as they participate in this emotionally challenging care. Health systems need to be structured so that nurses are not forced to leave their employment or to retire should they choose not to participate in MAiD, whether their reasons be related to conscientious objection, psychological sequelae, or other moral concerns.

**Equity**

Ethics in Practice 16-2, our second case study, shows how raising questions around equity, such as differential access to care based on place of residence, is an essential aspect to analyzing the ethics of end-of-life care. Nurse-scholar Kelli Stajduhar (2020) examines the ways in which people who belong to marginalized groups—those made vulnerable by housing instability, mental illness, substance use, street involvement, or racialization and colonization—are excluded from palliative care and its practitioners’ focus on quality of life and alleviation of suffering. She notes that “[a]s a concept, hospice and palliative care seems to be unanimously supported, but that is what it remains for some people: an idea that only becomes reality for the few who are privileged enough to have access to it” (p. 89). She further urges us to see how vulnerability to suffering is socially mediated; a product of one’s “location within the hierarchical social order within society, which encompasses not only political and economic inequalities but also a wider range of cultural determinants (e.g., the medicalization / pathologization of ‘at-risk’ populations, cultural views on the ‘worthiness’ of particular groups, etc.)” (p. 90). In a similar way, the 2017 CNA *Code of Ethics* expects that nurses will recognize that “vulnerable groups in society are systematically disadvantaged (which leads to diminished health and well-being)” (p. 19). Nurses, according to the 2017 CNA *Code of Ethics*, advocate for the quality of life of such people, and act to overcome the barriers to health care that they face.
“I’m a Writer”: Approaching Equity Through a Focus on Personhood

Anna is a community outreach nurse for a clinic specializing in the care of people in vulnerable housing in a major Canadian city. A typical day involves visiting her patients wherever they are, whether on the street or in shelters, to provide whatever nursing care is needed. This morning Anna is going to see Bill at his home—a single room-occupancy dwelling in the core of the city. As she approaches the building on her bicycle, she is struck by the juxtaposition of abject poverty and gentrification on the same city block. Luxury condominiums rise to the sky, and artisanal boutiques and coffee shops dot the street at eye level, alongside several smaller dilapidated buildings that serve as rooming houses. Her purpose for today’s visit is ostensibly to dress a wound created by a diabetic foot ulcer, and to review some new prescriptions, but ultimately, she is there to check on how Bill is doing.

Over the last two years, Bill would regularly “disappear” every several months, avoiding all contact at the clinic and not answering his phone. About three months ago, Bill suddenly lost a lot of weight and became extremely weak. Because of an absolute refusal to go to hospital, Bill does not have a formal diagnosis, although Anna suspects he is in the advanced stages of a terminal cancer. Today, when Anna arrives, Bill does not come to the door, but he calls for her to enter. He has left the door unlocked and is slouched in a recliner by the singular window at the far end of the room. A cigarette hangs from his mouth and his eyes are half-open. Next to him is what looks like a new book—a 2017 version of *The Cambridge Companion to Canadian Literature*. Anna smiles to herself, remembering long conversations she’s had with Bill about the time he spent studying creative writing at university forty or so years ago. As Anna approaches, she asks Bill how he is feeling. “Like crap,” he replies.

As Anna dresses the wound on Bill’s foot, they talk about how things are going. Bill is getting progressively weaker. He eats almost nothing and spends all day and all night in his chair. Anna suspects that he can no longer walk to the bathroom, as she can smell urine. She offers to help Bill to the shower, which he refuses, though he allows her to help him to change his pants. As he stands, his knees buckle, and he becomes severely short of breath. He sits back down and curses. Anna has already talked to Bill about residential hospice, which he adamantly refuses. They will not let him smoke in his room, and regardless, he will not under any circumstances enter a health care facility.

He has told Anna of spending many years being turned away from emergency rooms, and being subjected to the judgmental gazes of nurses and doctors who believe that his life is nothing but the product of his own bad choices. He has told Anna that if he is going to die, he will do so here: in this chair, gazing out this window, where no one can touch him. She’s asked him whether she can continue to check in on him.
Assessing the Ethics of the Situation; Relationships, Goals, Beliefs, and Values

In this situation, it is apparent that Anna and Bill have established a trusting relationship. He invites her into his home, despite his deep mistrust of health care providers. This mistrust makes sense given the long-standing discrimination and stigma he has faced when engaging with the health care system. The 2017 CNA Code of Ethics articulates trusting relationships as foundational to ethical nursing practice: “Nurses build trustworthy relationships with persons receiving care as the foundation of meaningful communication, recognizing that building these relationships involves a conscious effort. Such relationships are critical to understanding peoples’ needs and concerns” (p. 8, emphasis in original). Here we see that Bill’s openness to Anna is not merely a chance alignment of personalities, but the result of a conscious effort on Anna’s part to engage with Bill on his own terms. She shows genuine curiosity about his life and admiration for his many strengths, beyond his current challenges. She takes a broad assessment of Bill’s situation, recognizing that the nursing task of foot care, while important, is only one small piece of a wider constellation of health needs and

REFLECTIVE QUESTIONS

1. Where do you think Bill should receive end-of-life care—is it safe for Anna to respect his decision to stay right where he is?

2. What is Anna’s role in this scenario?

3. What broader ethical considerations does this case raise about how we live, die, and care for one another in today’s world?

Assessing the Ethics of the Situation; Relationships, Goals, Beliefs, and Values

until that happens, to which his answer was, “Yes. You’re nice. You’re not like them.” As Anna packs up her supplies, she verifies that Bill has enough pills and enough cigarettes to last until his cousin’s visit in two days, when she will refill both. She also asks about the book on Bill’s table, which leads to a short conversation about his time at university. “I’m impressed you keep up with the current literature!” she says. Bill musters a sly smile. “Of course,” he answers. “After all, I’m a writer.”
concerns. Likewise, she affirms Bill’s identity not simply as a person who is vulnerable and marginalized, but also brilliant and creative.

The 2017 CNA *Code of Ethics* reminds us that “Nurses support each other in providing person-centred care” (p. 15). Anna’s commitment to holding this broader view, refusing to limit understanding to narrow stereotypes and deficit-based discourses, is an example of person-centred care. However, as this passage from the 2017 CNA *Code of Ethics* makes clear, such care is not only realized from within the individual nurse-patient relationship, but requires the support of others. This raises other questions about the relationships at play in Anna’s work environment. Does she have nursing colleagues on whom she can depend, to help her think through the challenges she faces in caring for Bill and to support her in meeting his goals? Do the leaders and organizational structures of her institution facilitate or hinder the broad approach that she takes to her nursing practice? For example, does Anna have the time, space, and resources required to attend to her patients’ needs in a fulsome way? How can advanced practice nurse leaders be involved in resource allocation? What are the implications for future policy work?

**Reviewing Potential Actions in Light of a Patient’s Values and Sense of Dignity**

Bill’s living situation, and the choices he makes as his health worsens, are likely to provoke moral uncertainty in nurses responsible for his care. According to the 2017 CNA *Code of Ethics*, “Nurses support persons receiving care in maintaining their dignity and integrity” (p. 12). But what does dignity mean in this context? The challenges Bill faces in completing basic activities of daily living, such as toileting, are an important threat to dignity. But the prospect of having to leave his home to enter an institutional setting where he has felt disrespected and dehumanized is also a threat to his dignity. One of the ways that nurses honour dignity, according to the 2017 CNA *Code of Ethics*, is by encouraging people at the end of life to be clear about what they want. Nurses “listen to a person’s stories to gain greater clarity about their goals and wishes” (p. 13). By checking her own assumptions about which types of settings are
most appropriate for Bill to experience a dignified end to his own life, and by listening to Bill’s stories and accepting without judgment what he values and why, Anna can come to a deeper understanding of what ethical end-of-life care might look like for Bill, and how to support this from within whatever context he chooses for himself.

**Selecting an Ethical Action: Maximizing the Good**

Through multiple conversations with Bill, Anna comes to see his desire to die at home as his way of exerting agency at the end of his life, which has been marked by multiple losses and hardships over which he had little control. She recognizes that being the only person that Bill trusts poses risks to them both; shouldering full responsibility for Bill’s safety and well-being could become unsustainable for her over time, and if Anna is unavailable to care for Bill, he will be left with no one.

Anna arranges for an NP from a local hospice, with expertise in trauma-informed care and harm reduction, to accompany her on one of her visits with Bill. During this visit, the three of them review Bill’s symptoms and adjust his medications to alleviate his shortness of breath. The NP assures Bill that if at any point he decides he would like to transfer to the hospice, she has confirmed that volunteers and paid staff are available to take him outside—even after he can no longer walk—to smoke. In the meantime, the NP will remain available to Anna to adjust Bill’s treatment plan as needed to keep him comfortable and support his decision to remain at home.

Anna also connects with Bill’s cousin, Charlene, with his permission. She coordinates the time of her next visit to happen while Charlene is present with Bill. She learns that Charlene and Bill share a strong bond and are an important source of support to one another. The three of them talk about Bill’s health, and their shared commitment to help Bill die comfortably. Over the next several weeks, Anna focuses her visits not only on how Bill is doing, but also on Charlene and her feelings in anticipation of Bill’s death. Anna asks to hear stories of their relationship and of the adventures that Charlene and Bill have had together. Anna also connects Charlene with the same local hospice, which offers resources to support her in grief, both in advance of and after Bill’s death.
In discussions with nursing colleagues, Anna reflects on the many injustices that Bill has faced, in relation to his experiences of health care as well as housing. She reflects on the growing invisibility of people like Bill and Charlene, given the widening gap between those with and without money in this neighbourhood. Anna connects with her provincial nursing association and finds a group focused on palliative care and social justice. There, she meets colleagues with similar values, experiences, and observations, and together they strategize about how to advocate effectively at a systems and policy level for people like Bill who face structural dis-advantage in end-of-life care.

**Sexual and Gender Diversity**

As highlighted in the previous Ethics in Practice case, nurses encounter many intersecting axes of social vulnerability in their end-of-life care practice. One such axis, which has received relatively little attention in Canadian research about end-of-life care, is sexual and gender diversity. In this final section, we focus specifically on some of the unique considerations for enacting a palliative nursing ethic with members of LGBTQ2 communities.

In our own practice, we have noticed that frequently, disclosure of LGBTQ2 identity in palliative care happens organically, when nurses create a trusting context in which the person feels at liberty to speak about their identity and their relationships. Although the creation of this relational context is admirable, a nurse in such a situation might ask themselves a critical question: Why did I not already know this about this person? In a focus group of LGBTQ2 seniors about their hopes and fears approaching the end of life, Wilson and colleagues (2018) note that systematically asking people about their sexual orientation and gender identity is not routine practice in Canadian health care. This has consequences for the visibility of LGBTQ2 people in care, contributing to their erasure. As one participant in this study commented: “There are LGBT people in every [care setting] ... most of them are in the closet or back in the closet again” (p. 28). As LGBTQ2 people age and approach the end of life, many worry about having to keep their sexual and/or gender identity secret. In other words, they worry about being forced back
into the closet. In the focus group study just referred to (Wilson et al., 2018), one participant spoke of knowing someone who received good care at the end of his life, but “at the cost of him saying ‘don’t tell anyone I’m gay’” (p. 28). This fear is particularly painful, given that LGBTQ2 seniors will often have only come out of the closet later in their lives. For many, it was not safe to do so earlier.

Importantly, outright homophobia or transphobia by care providers is not the only cause of retreating into the closet. Aging LGBTQ2 people may assume that nursing care will be unsafe, until it proves itself otherwise. This fear comes from having lived through decades of oppression, stigma, and a shifting legal context that has only recently begun to affirm their dignity as fully human. LGBTQ2 people are therefore pushed back into the closet, not just by overt instances of hostile discrimination, but also when they are lacking an explicit confirmation that the settings and providers tasked with their end-of-life care will affirm and celebrate their LGBTQ2 personhood.

Ethical end-of-life nursing requires awareness of, and a commitment to address, the reasons that LGBTQ2 communities may rightfully mistrust our end-of-life care systems. One important consideration is that in Canada, much palliative care is delivered within faith-based institutions. Although the nursing care delivered in such institutions may or may not have any actual connection with religion, many LGBTQ2 people will be triggered by the mere thought of having any kind of religious organization provide their health care. This grievance comes from the legacies of oppression—historical and contemporary—by some religious institutions against LGBTQ2 identity. As articulated by one participant in the Wilson et al. (2018) study:

“Let’s put that on the table right now ... I’m very frustrated and angry about faith-based approaches to anything regarding our health. If you choose that and wish that, cool. I’m sure there’s many places you can access, but to even consider it or think about being what I would call trapped or imprisoned in a faith-based institution makes me nearly apoplectic.” (p. 27)
While some people in the LGBTQ2 community, such as the person quoted above, experience faith-based institutions as a symbol of their own oppression, for others organized religion is a valued source of spiritual meaning. Cheri DiNovo (2021), a United Church of Canada minister and former politician (who passed into law more pro-LGBTQ2 legislation than anyone in Canadian history), writes the following about her own experience of being both a queer woman and a person of faith: “[When] I find myself in another city looking to worship in a local church, I look for similar markers: pro same-sex marriage, anti-war. I’ve never been disappointed in finding such a church anywhere in the world. The Christian Right (which is neither) gets the press, but there has always been an alternative” (p. 47). The important lesson here is to respect and acknowledge how and why some LGBTQ2 people will fear for their dignity within faith-based health care delivery, while also resisting a master-narrative that erroneously conflates all organized religion with anti-LGBTQ2 bigotry. As DiNovo writes about her own identity, “At my queerest I’m a person of faith. At my most faithful I’m most queer. There’s no separation. Never was” (p. 196).

Beyond dimensions of faith, the culture of institutions providing end-of-life care in Canada are characteristically heteronormative and cis-normative. This means that even in the absence of homophobic or transphobic attitudes, which are always unacceptable, care providers who are not themselves members or strong allies of LGBTQ2 communities will often lack the cultural competence to fully engage with the intricacies, struggles, and triumphs of what it means to have lived an LGBTQ2 life in this world. These gaps have important implications for the ethos of palliative care nurses, whose practice revolves around family-centred care, legacy building, storytelling, and grief work. In order for LGBTQ2 people to benefit from relational practice, they require more than just not to be discriminated against. Nurses and other providers need to be genuinely committed to understanding and honouring them—their individual and collective histories, grief, and resilience. As one participant in the Wilson et al. study (2018) stated: “[I]t’s not an easy thought to think in later life [about] finding a new doctor who understands what you’ve been through” (p. 27).
Conclusion

There is no standard nursing script for ethical engagement with people as they approach their death, weigh their options, and make their choices. A typical nursing day involves having to move in and out of peoples’ stories, adjusting to the rhythms and dynamics of each one to create moments of relational connection that are attuned to whatever specifics are in play. Such movement can mean encountering different situations that initially appear similar, but on closer examination reveal themselves to be radically unique. By committing to a form of narrative proximity (Malone, 2003), nurses contribute to safe spaces for people to work through what matters most to them, and to craft an end-of-life experience that meets their needs and aligns with their values. To do this, nurses must really hear the concerns that people articulate, and accept whatever interpretations they develop.

The nurses in each of the two Ethics in Practice scenarios presented in this chapter are, in different ways, role models for enacting a relational ethic of end-of-life care, where dignity and justice are honoured and promoted in everyday practice. Of course, the successes portrayed in scenarios such as these depend not only on the competence of individual nurses, but on the structures and systems that facilitate—or interfere with—ethical nursing practice. Advanced practice nurse leaders are key in advocating for policy change to ensure that the appropriate structures and systems are available. At the institutional level, clinical and political leadership is essential in creating nursing practice environments where nurses can provide ethical nursing care. Leaders who support nurses in focusing on the “big picture” of what people face as they die, and practice environments that reflect an ethos where the concerns of dying people truly matter, are two examples of structures that influence nurses’ moral agency in end-of-life care.

In this chapter, we have invited reflection on the myriad ethical complexities that characterize experiences of dying and death. Such complexity is inevitable regardless of the actual options chosen for end-of-life care or the places in which they are enacted. Through their commitment to honour and engage this complexity, rather
than rushing to simplify or solve it, nurses offer crucial support to people approaching, and grieving, end-of-life situations.

QUESTIONS FOR REFLECTION

1. In this chapter, we have suggested dignity and justice as two core values that underpin an ethical philosophy of practice for end-of-life care nursing. What other values would you consider core to this philosophy?

2. How can we best enact a palliative care ethic, when the person receiving care does not share the same values around suffering and its alleviation as we do?

3. The two cases in this chapter are about MAID and equity in care. In what ways do these two topics intersect? In other words, what implications do you see for MAID policy and practice, when approached from a social justice lens?
Endnotes

1 Our analysis of each case follows a series of questions for ethical reflection, taken from the Oberle and Raffin model as adapted by the Code of Ethics for Registered Nurses (CNA, 2017).

2 The bill requires that patients have a “grievous and irremediable medical condition” that is not related to mental health. To use the terms of this chapter, people seeking MAiD eligibility have to show a physician that an incurable physical condition is causing existential suffering and a loss of personhood.

References


SECTION 3

Navigating Horizons for Health Care and Nursing Ethics
“During the past two decades, the field of human genetics has undergone significant change. The sequencing of the human genome has fueled understanding of the relationship between genetic variation and human health. Demand is such that clinical nurses and physicians working in a variety of clinical disciplines are now required to integrate genetics into routine care.” (White et al., 2020, p. 1149)

The Field of Genetics and Genomics

THE HUMAN GENOME PROJECT, an international effort to map the entire human genome physically and functionally, was completed in 2003. The completion of the Human Genome Project spurred on significant growth and development in the field of genetics and genomics. Initially, the field of genetic testing focused on determining risk based on family history and offering genetic testing for single gene disorders inherited in a predictable pattern, where testing was
available. Now genetic technology enables testing, genome sequencing, and screening for more than just single gene disorders; it also offers opportunities to understand the underpinnings of complex conditions, to determine whether a patient will respond favourably or unfavourably to certain pharmaceuticals (pharmacogenomics), to target cancer therapy, and to identify predispositions to future conditions. Preimplantation genetic diagnosis and prenatal testing, for example, allow prospective parents to predict and select risk of certain genetic conditions in embryos prior to implantation, or in developing fetuses during pregnancy.

Genetic testing and screening have evolved from being offered only in specialized tertiary or university hospitals to being readily available and used in primary care, cardiology, cancer care, and midwifery, among other places. Innovations in genetic and genomic technology have led to a significant decrease in cost and corresponding increase in accessibility to genetic testing and services. Over the last twenty years—the emergence of direct-to-consumer testing—has changed the landscape of genetic testing (Allyse et al., 2018). At-home test kits can now be accessed to obtain information about an individual’s geographic ancestry, as well as their predisposition for certain conditions in the future.

Development of genetic and genomic technology has led to a concomitant recognition of the need for legislation and guidance about acceptable use of such technology. For example, there have been calls for international moratoriums on gene cloning and use of human germline editing (i.e., technology that changes heritable DNA in sperm, eggs, or embryos) to make genetically modified humans (Lander et al, 2019). Some countries with more widespread access to genetic and genomic technologies have put legislation in place to prevent forms of genetic discrimination in employment and life insurance, providing protection for individuals seeking genetic or pre-disposition testing for personal health and life planning (Genetic Information Nondiscrimination Act, 2008; Office of the Privacy Commissioner of Canada, 2017). In addition, professional bodies have offered guidance around key areas of ethical complexity including genetic testing in the pediatric context and the return of incidental findings, which we discuss later in this
chapter (Boycott et al., 2015; Committee on Bioethics, 2001; Miller et al., 2021).

Genetic and genomic research has also resulted in problematic practices, particularly for groups marginalized in Canadian and United States (US) health systems (e.g., Indigenous and racialized people). For example, there are multiple incidences of Indigenous groups being subject to genetic research to which they did not consent (Begay et al., 2019). Mistrust of genetic research is also apparent in research recruitment disparities among Black Americans. Research that fails to account for the immense genetic diversity within marginalized communities may lead to further health disparities (Scherr et al., 2019).

Clinical applications of genetic and genomic technologies hold potential to relieve suffering and promote well-being. However, they also raise ethical concerns in relation to marginalized populations. Of significant concern is the potential for eugenic applications which target certain genes based on subjective views of the burden of living with conditions related to particular genetic expressions. Thus, further advancements in genetic research carry implications not only for the human genome, but also for the value of human diversity within our societies.

In this chapter, we begin with an overview of genetic and genomic tools now used in a broad range of health care settings. These include genetic testing for single gene disorders, genetic screening, whole exome and whole genome sequencing, direct-to-consumer testing, prenatal screening, and preimplantation genetic diagnosis. We discuss complexity in analysis and interpretation of genetic findings. Lastly, we highlight ethical issues relevant to nurses and advanced practice nurse leaders related to informed consent, variants of uncertain significance, incidental findings, continuation and termination of pregnancy, and access to genetic technologies.

In the section *Counselling Individuals and Families*, we focus on decision making surrounding genetic and genomic technologies for individuals and families. We highlight the relevance of genetics and genomics throughout the human life cycle through an exploration of prenatal genetics, newborn screening and sequencing, inherited conditions with pediatric and adult onset, and multifactorial disorders which emerge in adulthood. We identify
how approaches to genetic counselling for people facing difficult decisions can effectively be grounded in feminist, relational ethics. Finally, we discuss ethical challenges in counselling related to working with families, newborn screening, genomic sequencing, prenatal and preimplantation genetic technologies, direct-to-consumer genetic testing, and genetic enhancement.

In the section Genetics, Identity, and Society, we consider the intersections of genetics and identity; for example, how human identity relates to genetics and how access to genetic information can shift identity. We consider the role of dominant cultural values in shaping biases concerning “favourable” and “unfavourable” traits and how such assignations can lead to practices, policies, and research that are arguably eugenic in nature. Here, we explore challenging ethical questions on how we should proceed as our technological capabilities continue to expand.

Finally, in the Practical Challenges and Opportunities for Nurses section, we include an overview of the role of advanced practice nurses in supporting individuals and families making decisions related to genetic testing. Areas of focus include education surrounding genetic and genomic technologies, communication with patients and families, decisional support grounded in relational ethics, culturally safer practices, and policy. Throughout the chapter, we provide several case examples to highlight common ethical challenges related to genetics and identity in diverse Canadian health care practice settings.

**Genetic and Genomic Testing and Screening**

Genetic testing initially focused on identifying a specific, known, disease-causing mutation in a single gene, such as one of the known mutations in the BRCA1/2 genes associated with hereditary breast and ovarian cancer. As technology has evolved and costs of testing and analysis have decreased, further options have become available (Guzauskas et al., 2020; National Human Genome Research Institute, 2021). For example, an individual with a personal history of inherited cardiomyopathy can now access gene panel testing, which looks for mutations in multiple genes associated with this condition. Additionally, over the last decade, more patients have
been offered whole genome sequencing or whole exome sequencing (that is, the part of the genome usually correlated with genetic conditions). A child with an undiagnosed developmental difference (e.g., significant cognitive delays and physical differences) can, for instance, have either their whole genome or exome sequenced to determine if there is a genetic basis for their phenotype (Elliott et al., 2019; Ontario Health [Quality], 2020).

There are also a number of technologies that may be used during the prenatal period. One is genetic screening, which determines, for example, whether a pregnant person may have an increased chance of carrying a fetus with a chromosomal difference such as Down syndrome or Trisomy 18. Screening tests are followed by diagnostic tests, such as amniocentesis or chorionic villus sampling. These diagnostic tests can pinpoint single gene conditions such as cystic fibrosis, alpha and beta thalassemia, and autosomal dominant polycystic kidney disease. Preimplantation genetic diagnosis is a tool that enables genetic profiling of an embryo during in vitro fertilization (IVF) prior to implantation of the embryo. Genome editing—involving targeted genetic modification of a cell’s genome through cutting, inserting, or otherwise altering DNA in specific somatic (non-heritable) cells in an individual with a specific genetic condition—offers potential treatment promise for those with genetic conditions. More controversially, the ability to perform germline editing (on sperm, eggs, or embryos) is now more technologically feasible. This process—which affects all cells in an organism—ensures that genetic conditions are no longer passed down through generations. However, this technology is not available clinically due to an international moratorium based on ethical and safety concerns. These concerns relate to the moral status of the embryos and the potential for permanent modification on the germline to affect future generations, as well as off-target implications whereby germline editing results in unplanned, harmful changes (Greely, 2019; Hildt, 2016; Ormond et al., 2017).
Informed Consent

One of the foremost ethical considerations in genetic and genomic testing relates to ensuring adequate, informed consent. Traditional, individualistic models of consent may not be sufficient in genetic counselling. This is a uniquely complex area of health care: because genes are familial in nature, testing may have implications and ripple effects not just for an individual patient, but also for their close and more distant relatives, as well as their wider community. In the Ethics in Practice example that follows, we describe some of the concerns that are evident in relation to genetic testing.

ETHICS IN PRACTICE 17-1

Informed Consent

Abigail is a nurse practitioner (NP) in a remote community with a large Indigenous population. Abigail was born in the community and has served as the primary health care provider there for over a decade. Bill, one of Abigail's Indigenous patients, recently came to her with a letter he received from a cousin whom he has not seen in years. The letter states that his cousin, who now lives in a large city, has been found to have long QT syndrome. This condition is prevalent in certain Indigenous communities and causes an abnormal QT heart rhythm and may result in seizures, fainting, or even sudden death. The letter states that Bill is at risk and should get tested. Bill is distressed and very anxious upon receiving this information. He states that he is concerned about what might be done with his DNA if he goes ahead with testing. However, he is also concerned about his duty to share this information with his own siblings and children, whom Abigail also sees as part of her practice.

In the pediatric setting—or in any setting where testing may benefit someone who does not possess the capacity to consent—issues related to autonomy and choice can become even more complex. In general, there is recognition that a child or youth should only be offered genetic testing that will benefit them in their childhood. For adult-onset disorders, professional guidelines maintain that, in general, a minor’s self-determination should be respected by delaying testing until the minor can make a fully
autonomous choice as an adult (Committee on Bioethics, 2001). However, this has been challenged as being overly paternalistic in the context of minor youth who have the capacity to make such decisions, particularly when the genetic information may have immediate impacts in terms of life planning and relieving anxiety about the unknown. Additionally, while this approach generally stands up to ethical scrutiny, it is complicated when incidental findings revealed through pediatric genome sequencing may reveal not only the child’s risk for an adult-onset cancer, but also their parent’s risk. Revealing adult-onset conditions during childhood may take away a child’s right to decide, but the child also has a vested interest in their parent’s well-being which would necessitate disclosure of the incidental finding. Knowledge needed for parents to take preventative measures (such as, screening or prophylactic surgery) may be identified through such testing; however, disclosing this information is at odds with delaying revealing a child’s risk for an adult-onset disorder until the child has the ability to make an informed choice about whether they want to receive the information (see Chapter 12 for more information about children and informed consent).

**Variants of Uncertain Significance and Incidental Findings**

Another ethical issue that arises in genetic counselling concerns *variants of uncertain significance*. These occur when a mutation in the gene of interest being tested is revealed, but it is unclear whether this mutation is benign or disease-causing. Sensitive disclosure of such findings is essential to avoid unnecessary anxiety and also ensure follow-up is possible if this variant is reclassified in the future as either benign or disease-causing. Discussions regarding whether the health care provider or the patient is responsible for initiating future follow-up to determine whether a variant is reclassified as benign or disease-causing are complex, and involve ethical tensions related to duties of health care professionals, the length of the therapeutic relationship, and potential for disclosure to result in harm or benefit.

Incidental findings are those known to have clinical significance that are uncovered unintentionally in the course of testing. Such findings are not related to the initial reason for the test and have
been the subject of many ethical debates, including the “right to know” versus the “right not to know” (Christenhusz et al., 2013; Ells & Thoms, 2014). Some have argued that there is an ethical duty to disclose findings that are clinically actionable, as many people may wish to be informed; for example, in situations where individuals may decide to access further screening, or pursue prophylactic surgeries to reduce the risk of developing a health condition (Green et al., 2013; McGuire et al., 2013). Others have argued that mandatory disclosure fails to recognize that a significant portion of individuals at risk for genetic conditions prefer not to know their risk, as knowledge of this risk may cause unwanted distress and anxiety (Burke et al., 2013). Determining whether an individual would want to know about their incidental findings as part of the informed consent process may decrease the potential for unforeseen moral dilemmas on the part of clinicians (Cox & Starzomski, 2004). However, unforeseen incidental findings are sometimes unavoidable. As noted above, particularly challenging ethical issues may arise in the context of pediatric testing, wherein the incidental finding may only have relevance for the patient decades down the line, but may be immediately salient for the parents (and thus impactful, too, for the child).

Prenatal Screening and Testing

Genetic screening and diagnostic tests available during the prenatal period may lead to challenging ethical decisions related to continuation or termination of pregnancy. Preimplantation genetic diagnosis exacerbates already heated ethical debates around in vitro fertilization regarding the burden on the individual undergoing fertility treatments, the inequities in access to this technology, and the creation of multiple embryos, many of which will ultimately be used for other purposes (e.g., donated for research) (Dondorp & de Wert, 2019). Human germline editing, while not currently available, has raised similar ethical questions, in addition to bigger concerns related to the acceptability of permanently altering the human genome (such that changes are inherited through generations). Additionally, the safety of such technology and potential for off-target effects (whereby there are unintended changes in other areas of the genome with unknown consequences) has also raised con-
cern (Ormond et al., 2017). Each of these prenatal technologies raises ethical questions related to justice; they underline, for example, issues of ableist stigmatization of genetic difference, discrimination, and eugenic messaging. Issues of equity also arise related to access and costs of these technologies.

**Direct-to-Consumer Testing**

Another ethical complexity that has become increasingly apparent over the last decade involves access to genetic technologies provided by direct-to-consumer genetic testing companies. Home testing kits are available for a nominal fee, usually in the range of one to two hundred dollars. Individuals interested in learning more about their genetic histories can send blood or saliva samples to these companies for analysis. While some of the results may be low stakes or curiosity-driven, such as ancestry or risk of male pattern baldness, implications of other test results may be more profound in terms of their clinical significance (e.g., risk for developing Alzheimer’s disease). A multitude of questions related to the ethical rationale for offering these tests has arisen, including how to ensure proper informed consent, accuracy of results, protection of personal data, and equitable access to testing. There are also implications for health care systems that are burdened with helping patients make sense of the test results (Caulfield & McGuire, 2012; Hawkins & Ho, 2012; Middleton et al., 2017).

In this section, we have highlighted the evolution of genetic and genomic technology over the last several decades, along with the simultaneous emergence of ethical considerations in relation to the use and application of these technologies. While questions related to discrimination, ableism, privacy, consent, and the familial implications of genetic and genomic testing in an individualistic health care model are not new, the increased availability of such technology has meant that the public, and accordingly health care systems more broadly, increasingly have to grapple with these complex ethical issues. As such, it behooves new and practicing health care providers to have awareness of these issues.
Counselling Individuals and Families

To illustrate the ethical complexity of genetic and genomic technologies, it is helpful to consider how genetic conditions manifest throughout the lifecycle and how relevant technologies are applied in clinical practice. Preconception or prenatal genetic offerings provide an opportunity to assess risk for certain conditions that manifest during pregnancy due to family history, gamete age, or generalized chance for a condition in a given population. It is more common for genetic testing to be offered following initial screening tests (e.g., non-invasive chromosome screening) or ultrasounds that suggest certain genetic conditions. In these circumstances, further and more invasive testing (e.g., amniocentesis) may be offered to either confirm or rule out a condition. This ensures that the locally available range of reproductive choices, including termination of pregnancy, can be offered during the prenatal period. In the pediatric genetic context, counselling surrounding testing is complicated by the potential for genetic information about a parent being revealed that may have immediate relevance for the health of the parent, and, therefore, the well-being of the child and the entire family.

Genetic testing and genomic sequencing in the adult context also generate discussion and debate. With the increased availability and awareness of genetic tests, practitioners outside specialized genetic centres have become more familiar with obtaining family histories and offering (and interpreting) genetic tests. For example, practitioners in the fields of neurology, cardiology, and oncology have developed specialized clinics to identify and care for individuals at risk for certain conditions (Lynce & Isaacs, 2016; Musunuru et al., 2020; Rexach et al., 2019). This care often includes regular screening tests, prophylactic risk-reducing surgeries and implantation devices, and behavioural modification. While the ability to act on genetic findings to modify risks of clinical manifestation of certain aspects of disease has improved, complexities related to predictive and confirmatory testing remain significant.
Genetic Counselling and Relational Ethics

Interpretation of Findings

Genetic and genomic testing mechanisms—and the ensuing results—are complex and require skilled analysis and interpretation. Sound genetic counselling practices are necessary to ensure patients are adequately supported and can provide fully informed consent before undergoing testing. Genetic counselling entails an explanation of complex inheritance patterns, including autosomal dominantly inherited conditions (in which first-degree relatives of an individual with a genetic condition have a 50% chance of inheriting that condition), autosomal recessive conditions (in which there is a 25% chance of having a child with the same condition), X-linked conditions (which usually manifest more severely in males), and multifactorial conditions such as, cardiovascular disease or cancer, which are caused by many genetic and environmental factors (Canadian Association of Genetic Counsellors, n.d.; National Human Genome Research Institute, n.d.; Resta et al., 2006).

Counselling must be tailored according to the specific type of genetic test and expected result. For example, single gene, fully penetrant disorders are conditions that have a clear inheritance pattern and will definitely lead to predictable clinical manifestations (e.g., hemochromatosis). The term variable expressivity is used when the same genetic profile can have different manifestations, even within a single family (e.g., Marfan syndrome). Reduced penetrance is present when some individuals with a genetic mutation will not manifest a condition while others will (e.g., familial cancers). Highly complex multifactorial inheritance involves several genetic and environmental factors that can lead to a condition (e.g., heart disease and diabetes). Finally, interpretation of test results involves explanation of variants of uncertain significance and incidental findings.

Relational Ethics

Genetic counselling is strongly rooted in feminist relational ethics approaches (i.e., ethics of care) (Jamal et al., 2020; Ryan et al., 2015). In contrast to predominantly individualistic health care models,
trained genetic counsellors embrace the interconnectedness and interdependence of individuals. The context in which patients live, as well as their relationships with others, help shape the ways in which counselling and health services are provided. Using relational ethics supports practitioners to respectfully attend to the complex interplay of familial, social, and cultural relationships, as well as power dynamics, learning styles, and cultural ways of knowing (Hauskeller, 2020; Noddings, 2012). In addition to its grounding in relational ethics, genetic counselling is non-directive in nature, meaning practitioners aim to create environments in which empathic listening supports patients to feel understood, to have their personal values clarified and validated, and to reflect and make choices that are in keeping with their beliefs and circumstances.

**Ethical Challenges in Practice**

**Familial Risk**

One complicating factor in providing genetic counselling relates to the familial nature of genetic conditions. For example, when counselling an individual about their familial risk for polycystic kidney disease, a practitioner needs to consider the familial and cultural context of decision making. This includes addressing concerns related to genetic discrimination, as well as contending with ethical tensions surrounding the right not to know one’s genetic information. When patients choose not to know, practitioners may experience moral distress as they attempt to balance their duty to protect patient privacy and confidentiality with their perceived and sometimes real duty to warn at-risk relatives of their genetic predisposition. However, as many common conditions—such as heart disease, diabetes, and cancers—are multifactorial in terms of genetic and environmental risk factors, it must be taken into account that risks may be over- or under-estimated. In the Ethics in Practice example that follows we describe challenges that occur in genetic counselling when respecting the divergent wishes of multiple family members.
Relational ethics approaches can be particularly helpful in navigating complex family situations and balancing the needs of various parties whose genetic information is inextricably connected. Practitioners must be skilled at navigating familial and psychosocial implications of genetic knowledge and technologies, such as the potential for family conflict and genetic discrimination. For example, applying individualistic models of consent may be challenging when there are familial and community ramifications to genetic and genomic testing. Practitioners can encourage patients to consider the broad range of repercussions of testing on family members, including implications for genetic status as well as mechanisms to balance harms and benefits. This is done by assisting patients in sharing information with their family members via family counselling sessions or informational letters. The sessions or letters provide relevant information about the condition, inheritance, and potential for testing, which family members can then use to inform their personal decision making.

Use of newborn screening and sequencing technologies has also stimulated ethical debate related to consent, utility, and potential for discrimination. Newborn screening is available and offered
under public health schemes in many countries. Use of these screening programs helps practitioners identify rare metabolic, endocrine, blood, and other disorders in the first few days of life, so that effective treatment may be provided. While such testing in and of itself is widely heralded for improving and lengthening lives, questions have arisen related to appropriate consent on the part of parents, both for the testing itself and for the use of leftover samples for population health planning and research purposes. Utility is also questioned in terms of whether the testing yields significant, actionable health-related information. This is particularly important in relation to the potential for discrimination based on health conditions or predispositions identified through testing. In the Ethics in Practice example that follows we highlight the importance of cultural safety and humility in providing care related to genetics in the prenatal setting.

ETHICS IN PRACTICE 17-3

Navigating Cultural Safety in Prenatal Testing

Chioma is a nurse practitioner working in a clinic that provides primary care to new immigrant patients. One of Chioma’s patients, Fatima, recently went for a prenatal ultrasound. During the ultrasound she was informed that there were findings suggesting Down syndrome. Fatima was offered an amniocentesis test to confirm the diagnosis and have the option for termination of the pregnancy. She returns to Chioma for a follow-up clinic visit very upset. Fatima did not understand that the ultrasound could reveal this information. She now feels pressure to do the amniocentesis test even though she would never consider termination, as it is against her religious and cultural views. Fatima asks for Chioma’s guidance on how to proceed.

The use of genomic sequencing in the neonatal period is increasingly available, yet still expensive and not widespread. While such testing may identify the underlying genetic cause of a newborn’s congenital differences and suggest appropriate treatments, it can also flag variants of uncertain significance, incidental findings, and predispositions to adult-onset conditions (Johnston et al., 2018). This presents a challenge for practitioners in determining how
much genomic sequence information should be shared with parents, especially when such information may impact their child (e.g., a variant of uncertain significance that might lead to childhood onset diabetes) or even themselves (e.g., a genetic variant that leads to risk of sudden cardiac death).

**Prenatal and Preimplantation Genetic Technologies**

Prenatal and preimplantation genetic technologies have led to some of the most heated ethical debates regarding appropriate use of genetic technology. Such technologies have expanded reproductive choice and freedom, but also led to an increase in selective termination and a significant decrease in the number of children born with conditions such as Down syndrome and spina bifida. Meanwhile, disability communities have voiced eugenics concerns regarding “genetic genocide,” arguing that offering prenatal genetic screening and testing sends harmful messages to prospective parents about certain traits being inherently problematic, when they need not limit prospects of living a worthwhile life (Parens & Asch, 2003). These critiques extend to societal implications, as wide-scale use and acceptance of prenatal tests sends discriminatory messaging about disability rather than using resources to create more inclusive communities that address the needs of genetically diverse people.

These ethical tensions challenge practitioners to recognize and put aside their own beliefs and preconceived notions about what constitutes a life worth living. Practitioners are bound by their duty to ensure that patients are empowered to make choices that best reflect each individual’s values and context. Practitioners should also be prepared to address ethical concerns related to equity and justice for disability communities that are raised by these technologies.

**Accessibility of Services**

Direct-to-consumer tests, while considered by some as democratizing genetic testing by expanding access, have also impacted health care providers in settings ranging from primary care to specialized centres. As the availability and popularity of these tests rise, the health care system may face increasing pressure to manage the fallout of such testing, as people turn to the publicly funded health care
system for assistance in interpreting and responding to their results. This may lead to further diagnostic testing—such as, medical imaging or monitoring—which is particularly problematic when the predictive value of direct-to-consumer tests is poor, and people may receive unnecessary follow-up testing in an already overburdened public health care system.

Finally, while genetic technologies that can bestow a perceived enhancement or advantage (e.g., height, intelligence) are not currently clinically available, advancements in gene editing have made such services theoretically possible. Use of so-called “enhancement” technologies raises similar ethical concerns as prenatal testing: there is a potential for creating an increasingly disparate society. If only specific segments of the population were able to access such technologies, the creation of genetically privileged and marginalized classes could widen existing community and global inequities. As a society, as health professionals, and as individual practitioners, we must consider the ethics of genetic “enhancement,” and how we will respond to future requests to apply this technology in practice.

In this section, we have addressed ways in which genetic conditions affect people across the lifespan. We have also considered the expanded role of genetics in various health care settings. Relational ethics and non-directive counselling have been identified as central to the field of genetic counselling. Ethical challenges are not uncommon for those who help patients and families navigate complex issues related to privacy, confidentiality, consent, culture, diversity, and use of resources.

**Identity, Genetics, and Society**

The concept of identity concerns who we are, our unique characteristics, how we think about ourselves in relation to one another, and what connects us with others. If we conceptualize identity as socially constructed, we understand it as a phenomenon that emerges through interactions between the individual and others within society. In other words, identity is grounded in how we see ourselves in relation to others. Each of us likely has many facets to our identity; these may include race, Indigeneity, culture, gender,
sexuality, ability, and health. Many identity traits are willingly assumed by an individual; however, identity labels may also be assigned by others without consent of the individual. Some aspects of identity may shift over time in response to acquired information, individual and collective experiences, personal development, and shifting societal norms.

An individual can hold multiple, intersecting cultural and social identities. A person may be Indigenous (e.g., Anishinaabe, Métis), be religious (e.g., Jewish, Catholic), identify with a settler-state (e.g., Canada, United States), be part of a Queer community, be part of a Crip community, or even be a dedicated fan of a particular hockey team. Some identities are accompanied by strong genetic links, while others are not; for example, some families share strong genetic connections, while other families’ connections are primarily social (e.g., adoptive families). One well-recognized form of genetic identity is having a genetic lineage that connects a person to family members and to culture. Another form of genetic identity is connection to others who share a common genetic expression (e.g., Down syndrome). These identities may also intersect; for example, sickle cell disease is an inherited blood disorder most common among people of African, Middle Eastern, and Indian descent. The commonality between all of these identities is that they are relational: we are either aligned with, or differentiated from, others in society based on individual traits, many of which have genetic links.

Some aspects of identity, once developed, may remain fairly constant across the lifespan. However, there are also events that can shift a person’s identity surrounding family, culture, and health. Of relevance for us in this chapter are experiences related to genetic and genomic information which can affect a person’s identity. For example, genetic testing can reveal unexpected parentage or predisposition to disease. Discovering a genetic predisposition to a medical condition can have positive and negative aspects. It could lead to identification as an unwell person or, alternatively, to welcome connections with others with the same genetic condition (Zeiler, 2009). Responses can be complex. For example, a person receiving a negative test result for Huntington’s disease may feel both relief with regard to their own health and guilt if other family members have tested positive.
Since identity and its development occur in the context of society, it is important to consider the power of societal norms in shaping identity. A human society can be understood as a large social group of people who live in community and share a set of cultural norms. Identity traits that are considered normative (i.e., perceived as “normal”) vary across cultures and subcultures. However, within a given society, dominant views exist of certain traits as normative and non-normative; by extension, certain traits are therefore considered desirable or undesirable; for example, consider normative expectations surrounding race, gender, sexuality, and ability across various societies. Prevailing dominant cultural values can generate biases concerning favourable and unfavourable traits. An individual’s personal traits, whether self-identified or assigned by others, can determine their social location within a given community. For example, a Deaf or Hard-of-Hearing (DHH) person may be considered disabled by others in some spaces, but not within Deaf communities.

Certain groups may be subject to subtle or overt forms of discrimination or eugenics based on dominant cultural norms (e.g., conscious or unconscious bias against race, religion, sexuality, gender, or ability). Such groups may be deprived of liberties or resources necessary to thrive and reproduce. They may also be subjected to policies and services intended to prevent the existence of future members of the group (e.g., Down syndrome, DHH). Societal norms have the power to shape individual decisions, policy, and resource availability.

**Ethical Implications**

While some may consider genetic data to be purely objective, it is important to understand the value-laden nature of such information and the technologies used to acquire it (Newell, 2000). In this section, we consider ethical implications of how genetic information is obtained and applied in relation to individual identity, cultural identities, and prenatal decision making. We also examine how bias, expressed through genetic and genomic technologies, iteratively shapes how certain lives are valued in relation to others in ways that may alter the scope of human diversity.
Individual Identities

As noted in the section on Genetic and Genomic Testing, the ways in which people acquire genetic information is ethically relevant. Some may exercise autonomy in actively choosing to learn this information through, for example, seeking genetic testing for hereditary diseases like breast and ovarian cancer. Others may inadvertently discover identity-shifting genetic information through a direct-to-consumer test or a family member’s disclosure. In the case of disclosure by a family member, the individual may not have the opportunity to determine whether they want to know this information, but may benefit from opportunities to seek medical intervention (e.g., screening, prophylactic surgery). Regardless, knowledge of a single gene disorder or predisposition to a condition can change how a person views themselves and how they are treated by family members, health care providers, and society at large.

Furthermore, assumptions made by health care providers on the basis of someone’s perceived identity can determine whether they have access to health care services informed by genetic research. For example, multiracial people may not be offered screening for cystic fibrosis based on an assumption that they are not White and, therefore, have low risk of having a child with this condition. In another example, Black Canadians with sickle cell disease presenting in emergency departments with pain crises (i.e., vaso-occlusive crises) have reported encountering medical racism; they are racially profiled as drug-seeking, and denied timely access to necessary care (Favaro et al., 2021; Sickle Cell Awareness Group of Ontario, 2020). Ultimately, genetic information can significantly influence a person’s identity, their relationships with others, and their treatment in society (e.g., facing unjust discrimination or stigma, gaining access to social support).

Cultural Identities

On both individual and cultural levels, genetic information may be either highly valued or considered to have minimal utility. For example, within many Ashkenazi Jewish communities, genetic testing is considered integral to the health of their communities and future generations. Tay-Sachs disease is a life-limiting condition
that historically has disproportionately affected people of Ashkenazi Jewish descent; however, the disease has been largely eradicated within this population. Initiatives that have contributed to this include confidential marriage matching programs and pre-marriage genetic testing (e.g., *Dor Yeshorim*) within Orthodox Jewish communities. A connection between Jewish identity and genetic testing is demonstrated through the religious and cultural obligation to protect one’s health (Lipinsky, 2021). This is enacted through genetic testing to prevent multiple heritable conditions, thereby strengthening the genetic future of the community (Lipinsky, 2021).

Another example of genetic information being used to support specific populations has emerged in the form of human rights reparations. The right to identity has been established as a fundamental human right within the United Nations Convention on the Rights of the Child (United Nations, 1989). This right has been argued to include the right to one’s genetic identity. During the genocidal military dictatorship in Argentina from 1976–1983, thousands of adults targeted as political dissidents, or sympathizers, were killed or disappeared and approximately 500 babies born in captivity were given to people connected to security forces to be raised in what was considered a morally superior culture (Penchaszadeh, 2015). In 1983, a program was established to use genetic information both to identify human remains and to reunite abducted children with their grandparents.

In Canada, the period of mass child apprehension known as the “Sixties Scoop” resulted in thousands of Indigenous children being taken from their families and placed in adoptive families across Canada and the US, spanning the 1960s into the 1980s (First Nations Studies Program, 2009). Today, survivors continue to reunite with family members and communities with the assistance of direct-to-consumer genetic testing, social media networking, and generational knowledge of Indigenous communities (Martens, 2018). For many, these reconnections are immensely important to identity and well-being, but they do not erase the pain of being estranged from family, community, culture, and the land (MacDonald, 2019). In both the Argentinian and Canadian
examples, genetic information has been important in upholding the rights of stolen children to their cultural identities. While genetic information can help re-establish cultural identities, human cultures and cultural identities existed long before genetic testing. Genetic information can be useful in establishing connection for some groups, but it does not necessarily function as a sole basis of cultural identity and may even, in some circumstances, threaten strongly held identities. For example, Native American tribes and First Nations have resisted attempts to reduce identity to genetics, instead identifying concepts such as kinship and citizenship as holding cultural relevance for Indigenous identities (TallBear, 2013).

A specific area of ethical concern involves acts of biocolonialism, a term that can be used to describe harms that genetic and genomic technologies can cause when used to exploit knowledge and resources from Indigenous peoples (TallBear, 2013). In one such incident, a researcher took samples from the Nuu-Chah-Nulth First Nations (British Columbia, Canada), purportedly for arthritis research, but kept samples for many years, moved them internationally, and conducted highly sensitive research on unrelated topics without the consent of the Nuu-Chah-Nulth people (Wiwchar, 2013). A similar story unfolded in the Havasupai Tribe (Arizona, US) when DNA collected for diabetes research was used without individual or community consent for research on schizophrenia and geographic origins, the latter leading to conclusions that did not align with the tribe’s cultural beliefs and claims to traditional lands (Blakemore, 2018; Greenberg, 2020). In 2002, this led the Navajo Nation to issue a moratorium on genetic research. This topic is discussed in further detail in Chapter 2.

Unethical research conduct has perpetuated mistrust of Western medical researchers, contributing to underrepresentation of Indigenous people in genetic and genomic research on various diseases. This has led to efforts to understand Indigenous perspectives on genomic data and support Indigenous people to benefit from this research without exploitation (Morgan et al., 2018). Research ethics guidelines have been created for genomic research with Indigenous communities, specifically addressing the needs for cultural competency, collaboration, capacity building, community
control of data and biological samples, transparency, trust, consent, and accountability (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council, 2018; Claw et al., 2018; Taniguchi et al., 2012).

**Prenatal Decisions**

As noted in the previous section, one of the most ethically provocative areas of genetics involves prenatal interventions. Many decisions centre on whether to access screening for genetic differences and how to act on information obtained through any resulting diagnostic testing. In advance of pregnancy, people may think through what available prenatal screening they plan to access and how they will act on findings. For some, continuation of a pregnancy is the only acceptable option, while for others, termination may be preferred under some circumstances (e.g., Trisomy 18, Down syndrome). Other people may only consider these choices when faced with the results of screening. In the realm of pre-implantation genetic diagnosis, the timeline is moved back: these choices are not made about an already implanted embryo, but rather about which embryos will be given the opportunity to develop.

In terms of identity and prenatal decision making, a key question is: what does it mean to a person to be a “good (prospective) parent”? There is no simple answer to this question. Each person must answer for themselves the value-laden question of what prospective parents owe their potential future children and what constitutes a life worth living. Some people may highly value genetic diversity or believe that selecting children with specific genetic traits is inconsistent with their faith (e.g., “playing God”). Others may wish to give their potential future children every possible advantage through genetic and genomic technologies (Savulescu, 2001), believing it would be wrong to bring a child into existence with a preventable genetic condition. Finally, some parents who have a child with a genetic condition may wish to have another child via IVF with preimplantation diagnosis who shares DNA with their sibling, but not their genetic condition (i.e., saviour sibling), in hopes that the subsequent child’s stem cells can be used to treat the older sibling’s condition (Glover, 2006).
People’s values, which are connected to their identities, guide them as they make decisions about prenatal screening, continuation and termination of pregnancy, and preimplantation genetic diagnosis. However, individuals’ values may come into conflict and their identities may be challenged as they make these decisions. People’s partners and other influential figures in their lives (e.g., parents, friends, religious community members) may hold different values, adding complexity to decision-making processes. Ultimately, choices about prenatal interventions can influence both how a person sees themselves and how others view them.

**Genetic Diversity and Health Policy**

Underlying many decisions about genetic and genomic technologies are understandings of how genetic conditions affect people’s lives. These ideas can differ greatly and may be impacted by personal experiences and societal norms. For example, genetic diversity is separated into genetic norms as well as disabling genetic disorders on a societal level. What it means to be disabled is fundamentally based on socially constructed differences: these differences may be framed as undesirable at best, constitutive of a life not worth living at worst. If a difference judged to be disabling has a genetic link, screening may be developed. Once screening is available, a person may decide to terminate a pregnancy or not transfer an embryo based on available genetic information.

A key ethical tension that arises here is the eugenic application of genetic and genomic technologies to eliminate certain differences. While many people living with disabilities report good quality of life, perceptions of quality of life on the part of non-disabled people are often much more negative (Childress, 2003; Goering, 2008). The absence of disabled voices from discourses and policy development on the use of genetic and genomic technologies to eliminate disability is ethically problematic (Boardman et al., 2018). In recent years, the eugenic application of genetic screening has become evident, perhaps most clearly in the precipitous drop in births of infants with Down syndrome, with the termination rate for pregnancies with a positive screening result exceeding 90% in some countries (Will, 2018).
Ideas about what constitutes disability or socially unacceptable traits can shift over time. For example, some sexual orientations have been pathologized in the past, but are now considered a natural part of human diversity. Work is ongoing to depathologize certain genders, efforts that are reflected in human rights protections within Canada, notably through the recent addition of gender identity and gender expression as protected categories within the *Canadian Human Rights Act* (Bill c-16, 2017). However, given this history, it is understandable that people from marginalized groups may be wary of researchers seeking to pinpoint genetic causes of difference (e.g., gender identity), as there is potential for this information to not only shift how people identify themselves and are identified by others, but also for it to be used to attempt to eradicate segments of the population (Rajkovic et al., 2021). Another concern is the risk of creating a genetically privileged class with access to genetic screening, prophylactic measures, and pharmacogenetic treatments, alongside a genetically marginalized class without access to such technologies.

Finally, ableism not only manifests within the social construction of disability, but also in the (re)production of environments that are inhospitable to some, thereby reinforcing the idea of disability by limiting inclusion in society for many with genetic and other differences. From a disability ethics perspective, it can be said that it is society that is disabling (i.e., by creating and perpetuating norms of exclusion and oppression), rather than genetics or physiology (Newell, 2000). The ethical imperative to uphold the dignity and worth of all people requires us to consider how genetic and genomic technologies are applied on a societal level and the harms that may be caused by fostering bias against those identified as disabled. It calls into question why some forms of diversity are considered a disability or undesirable within certain cultures, as well as the implications of eliminating genetic differences based on potentially temporary socially constructed ideas of which lives are most worth living. To uphold the ideals of justice, equity, diversity, inclusion, and cultural safety, we must consider whether more resources should be allocated to creating societies in which people with genetic differences are better supported, to counteract eugenic elimination of such differences. As we seek to find the best pathways
forward as individuals, families, clinicians, scientists, and policy-makers, one thing is clear—we must ensure those with genetic differences are centred among the stakeholders involved in these deliberations (Conti, 2017). Ultimately, our use of genetic and genomic technologies, along with our treatment of people with genetic and other differences, reflects and shapes who we are as a society—our collective societal identity. For more discussion on disability please see Chapter 14.

We have explored the connection between genetics and identity on both individual and cultural levels. Genetic information can be used in beneficial ways; for example, to reduce the occurrence of genetic disease in a population and to restore genetic identity following human rights violations. However, genetic and genomic technologies can also be used in problematic ways—as evidenced through biocolonialism, unethical research practices, and eugenic policies—raising questions about the ethical use and limitations of these technologies. We have highlighted many ethical challenges in integrating genetic and genomic technologies within our health care systems in this chapter. Next, we focus on the role advanced practice nurse leaders can play in supporting patients, families, and interprofessional practice related to genetic and genomic technologies. We focus specifically on the areas of education, communication, relational ethics, cultural safety, and policy.

**Practical Challenges and Opportunities for Nurses**

**Education**

Nurses can access continuing professional education to increase their knowledge of genetic and genomic technology applications within health care. This includes understanding the impacts of having—and of being at risk for—genetic conditions, and how it affects patients and families across their lifespan (Sloand et al., 2018). Nurses can better support patients and families when they are familiar with the history and application of technologies that may be offered or accessed, including genetic testing, genome sequencing, prenatal screening, preimplantation genetic diagnosis, and, in the
future, gene editing (Lea et al., 2011). Knowledge of the availability, utility, and predictive value of certain tests, particularly those offered through direct-to-consumer genetic testing companies, may be helpful in supporting patients and families who have questions about testing and health risks. Advanced practice nurse leaders can make important contributions to the field, whether through self-study, continuing professional education, educating the public, or designing nursing courses about genetics and genomics.

**Communication**

The ability to communicate about complex genetic information at individual, family, and collective levels is essential for supporting decision making about genetic and genomic technologies (Medendorp et al., 2021; Snyder et al., 2009). Nurses are well-positioned to provide this support, drawing on education and experience in caring for patients and families, particularly those with complex relationships (Williamson & LeBlanc, 2008). Clear, tailored, and nondirective counselling can support informed consent about pursuing or declining testing or intervention. Building interprofessional relationships with genetics specialists and other health care providers in genomic medicine is key, as nurses increasingly need to have genomic acumen to support patients and families from their position as trusted health professionals (Montgomery, 2017). The ability of nurses to respond to patient questions (e.g., around informing family members, or whether and how to follow up on results of direct-to-consumer tests) and facilitate family and patient information sessions can reduce demand on genetic counsellors and geneticists, making care more accessible overall (Yoes & Thomas, 2020). Expanding the scope of nursing practice in this manner may also have important policy implications in terms of who can provide genetic services.

**Relational Ethics**

Relational ethics provides a strong foundation for engagement among nurses, genetic counsellors, geneticists, patients, and families. Drawing on relational ethics approaches, nurses are well-prepared to work with patients and families facing difficult
decisions, such as whether to pursue predictive testing or the continuation or termination of pregnancy (Evans et al., 2004). Similarly, working with patients and families to clarify their values and perspectives is essential for supporting sound decisions that may have profound impacts on identity. For example, nurses should be prepared to explore people’s ideas of what “a life worth living” means to them and how that shapes their decisions in relation to genetic and genomic technologies (Janvier, 2011; Janvier & Watkins, 2013). In addition, expertise or access to supports in areas such as grief counselling, conflict resolution, nondirective counselling, and anticipatory guidance will allow nurses to support patients and families through these complex and values-based decisions.

**Cultural Safety**

Cultural safety is defined by the BC First Nations Health Authority (n.d.) as “an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care” (p. 5). Broadly speaking, nurses can support cultural safety through learning about the histories (e.g., since time immemorial, colonization), cultures, ways of knowing, and health care experiences (e.g., medical racism) of the communities with which they work, through promoting mutual trust through open communication, and through providing individualized care that accounts for physical, psychosocial, and spiritual needs (Greenwood, 2019; Morgan et al., 2021). Nurses should be aware that based on their histories, identities, and lived experiences, people have diverse relationships with genetic and genomic technologies. Nurses should, therefore, avoid making assumptions about what decisions people will make based on stereotypes about cultural identities (Ward et al., 2016). In the context of genetic counselling, attention should be paid to historical context, trust, language, and beliefs, as well as individual and cultural values in relation to genetic differences, dis/ability, and relevance of genetic and genomic technologies to decision making (Morgan et al., 2018; Shen et al.,
Further information about cultural safety and research in Indigenous communities can be found in Chapter 2 and Chapter 5.

**Policy**

Nurses, alone or in collaboration with interprofessional colleagues, can play a key role in shaping institutional and governmental policy related to genetic and genomic technologies (Limoges & Carlsson, 2020). Examples of policy issues of relevance based on current literature include establishing roles and genetic and genomic competencies for nurses; resource allocation for patients and families (e.g., equitable access to testing, dealing with demands for unnecessary testing); limiting testing that leads to eugenic outcomes; and data privacy (Bottorff et al., 2005; Jamal, 2015; Taniguchi et al., 2012). In the future, issues such as germline editing and genetic enhancement may need to be addressed through policy review and development. Nurses can play an important role in ensuring relevant groups (e.g., the disability community) are represented in policy development processes, working toward a health care system that allows people to benefit from genetic technologies without reinforcing ableism or promoting eugenic practices.

**Conclusion**

In this chapter, we have reviewed genetic and genomic tools currently in use for testing, screening, and diagnosis, and how application of these technologies raises ethical issues related to informed consent, privacy, medical decision making, and resource allocation. We presented relational ethics and nondirective counselling as approaches applied in genetic counselling to support individuals and families making complex decisions. In discussing genetics in relation to identity and society, we delved into unresolved ethical concerns about how to balance beneficial application of genetic technologies with harms related to biocolonialism and eugenic practices. Finally, we suggest that advanced practice nurse leaders can make contributions within the area of genetics and genomics in five key areas. Through education, communication, relational ethics, cultural safety, and policy work, nurses can engage...
in interprofessional practice to support individuals, families, and communities around their use of genetic and genomic technologies. As the field of genomics continues to evolve, so too do fundamental societal questions, thereby stretching us to consider not only personal values, but also our collective societal values. Advanced practice nurse leaders have a key role to play in these conversations, and in contributing to shaping the future of genetic and genomic technologies within our health care systems.

**QUESTIONS FOR REFLECTION**

1. *Would you want to be informed by a family member if you were at risk for a genetic condition? Would you want to take a test for a genetic condition for which there is treatment? Would you want to take a genetic test for a genetic condition for which there is no treatment? What values inform your thoughts about notification and testing?*

2. *What skills do you have as a nurse that you could apply in counselling individuals and families about issues related to human genetics?*

3. *How does your identity influence your perspectives on genetic and genomic technologies? What perspectives or biases might you hold that could affect your ability to provide culturally safer care?*
Endnotes

1 The exome makes up only 1.5% of the whole human genome; however, all protein coding genes are found in the exome. As most genetic disorders are correlated with changes in the protein coding genes, exome sequencing is often used when trying to determine if there is a discoverable genetic cause of a condition. Exome sequencing and analysis is cheaper and quicker than whole genome sequencing.

References


CHAPTER 18

Promises and Perils of Digital Health Technologies

Elizabeth Peter, Charlene H. Chu, Rosalie Starzomski, Patricia Rodney, and Janet L. Storch

“[N]urses are a really, really important part of this picture, and there are ethical issues all along the technology pipeline. Nurses need to make their voices heard, from ideation, to implementation, to evaluation.”

IN THIS VIDEO INTERVIEW, the editors of Toward a Moral Horizon: Nursing Ethics for Leadership and Practice engage in discussion with two nursing scholars who have expertise in the field of digital health technologies. In this conversation, they talk about the role of nurses in the development, use, and evaluation of digital technologies in health care and nursing practice. A transcript of the conversation, which has been edited for clarity, is included below. Readers can view the video here https://doi.org/10.18357/9781550587128.
Rosalie Starzomski: Welcome everyone! This is a wonderful opportunity for us to have some conversation about digital technologies. We’re being joined in this session by Elizabeth Peter and Charlene Chu from the University of Toronto, and you will also see on the screen the three editors of the book, Dr. Paddy Rodney, Dr. Janet Storch, and myself, Dr. Rosalie Starzomski.

The plan for this session is for us to have a conversation about some of the promises and pitfalls related to digital technologies, particularly as they relate to nurses and nursing ethics and also health ethics research. So what we’re going to do to start is just some general introductions, and then we have some questions that we’re going to cover, but mostly we’re just going to have a conversation about this topic. You’ll have the opportunity to listen to this video and to view it but we’ll also have on the book site the opportunity for you to read a transcript of this session.

So as I mentioned, I’m Rosalie Starzomski, and I’m one of the editors of the book. I’m a professor at the University of Victoria, and if you’re interested in reading more about the biographies of myself, Jan, or Paddy you can do that on the book site. There will also be some information about Elizabeth and Charlene as well, but let me turn it over to Jan to introduce herself and say hello to everyone.

Janet Storch: Hi everyone, I’m really happy to be part of this session. I think it’s innovative and should be very authoritative from two experts that we have the benefit of having. So welcome to both of you, and just a little note about me—I am a Professor Emeritus from the University of Victoria, was at the University of Calgary teaching there, and Dean there. And basically, though, most of my life in academia has been at the University of Alberta.

Rosalie: Thank you Jan. So Paddy—

Patricia (Paddy) Rodney: I’m Paddy Rodney, and absolutely delighted to be here with these wonderful colleagues on a very interesting topic that’s clearly changing and evolving in our
society, so a really nice opportunity. My background is also in nursing and I graduated from the University of Alberta with a basic baccalaureate degree, did my master’s there, and also went on to do a PhD. I had a chance to teach with the University of Victoria for a while, and had a number of years working at the University of British Columbia, so I’m very happy to have a chance to work with wonderful colleagues, the faces we see on this screen. I’m really pleased to have this chance to have this discussion. I have a longstanding interest in health care ethics, that’s something that most of us share, and I think this is a really nice topic to also take an ethics lens to, so welcome everyone who’s watching this, thank you.

**Rosalie:** Thanks, Paddy. So, Elizabeth, would you like to say a little bit about yourself, please?

**Elizabeth Peter:** A personal thank you so much for being able to talk about a very much ever-evolving set of concerns and promises. My background is also in ethics. I’m a member of the Joint Centre for Bioethics at the University of Toronto, along with being a faculty member of the Bloomberg Faculty of Nursing, and got my PhD through their collaborative program in bioethics a number of years ago. My interest in this area has been mainly on the research ethics side, especially as we explore new ways of doing research using AI and machine learning, but I also have an interest in technologies as a whole.

**Rosalie:** Elizabeth, wonderful, and we’re just delighted that you’re able to join us. I’ll turn it over to you, Charlene.

**Charlene Chu:** Thank you to you and to Patricia and Jan for the invitation to be here. My name is Charlene Chu. I am an assistant professor at the Lawrence Bloomberg Faculty of Nursing alongside Dr. Peter, and my program of research is focused on designing and evaluating different technologies to improve the quality of life of older adults.
My PhD was at the Faculty of Nursing at U. of T., and it was focused on interventions for older adults, and then my postdoc was in a lab that was building AI and looking at different technologies, so my program of research melds these two areas. And so I’ve got a keen interest in looking at the ethical aspects of technology, throughout the implementation as well, and its implications for nursing practice and nursing education.

**Rosalie:** Thanks everyone, wonderful. Well, it’s just as my colleagues have said, delightful to have you both here, and Jan, Paddy, and I have had different discussions about some of the issues related to digital technologies as we’ve been working on the whole book.

And as some of the students that will be using this book in their graduate studies will be students who have a very keen interest in health informatics, I think this material will be particularly relevant to some of them, but of interest to everyone who’s involved in health care and working in nursing today, as it’s evolving so quickly. I think the fact that we can address some of the future challenges is a really good idea as well.

So let us start with the preliminary discussion about how do you think some of these digital health technologies are changing nursing practice, and do you have any thoughts about what some of the promises and pitfalls are? Why don’t I turn it to you first, Charlene?

**Charlene:** Sure, so that’s a great question. I think it’s an important question. I think it’s undeniable that digital health technologies are significantly transforming the practice of nursing and the health care industry as a whole. This includes how health care is accessed, how it’s delivered, and that of course has a direct impact on nursing practice. I think there’s lots of clear benefits and promises of digital health technologies.

As you know, the big five come to mind, which are: increased efficiencies—you have digital health technologies that help streamline documentation, automate tasks for example. So, for nurses that need to take a blood pressure every hour or transcribe paper orders from the physician, tech-
nology can help improve these tasks so that nurses are spending less time doing some of these tasks and spending their shifts on things like paperwork, for example.

It can help improve patient care, so technology allows for real-time monitoring a patient’s vital signs as well as other important information, which allows us to quickly identify any changes in health status, and we can intervene in a timely manner in order to address any potential health issues. Things like patient portals, remote patient monitoring, telehealth visits, for example. So all of these things can help improve patient access to care, improve patient care in general. Technology of course has implications to address equity issues as well.

Third, better collaboration, potentially. This allows nurses and other health care professionals to communicate in a timely manner. We have improved collaboration with better coordinated care so, for example, an NP can have the most recent lab results or medical images and so everybody knows what we’re talking about and the patient can get more expedi-tent care. I think from a structural perspective, we have improved data management in general, where the digital health technologies will help enable the creation of comprehensive and centralized patient data so it can be easily accessed by all members of the health care team. And again, this allows for more informed decision making and patient care.

And I think lastly, it can enhance patient engagement and education. So it allows for empowering patients because now they’re able to take a more active role in their own care. They can use apps to track their progress, monitor symptoms, communicate with their care team, just with a text through an app, and so we’re seeing these digital health technologies being used as a prescription and standardized care now. For example, after cardiac surgeries, where having an app like Medly to download, and having to use it at home is becoming standard practice.

So I think as technology continues to evolve we’re going to see more and more impact on nursing practice and on patient care. I think more significant kinds of questions around how technology is implemented, I think are important ones, and I
think there’s lots of perils. I think that was the word you used, Rosalie, and so I think the main ones that come to my mind immediately are the extent to which nursing work is either represented or underrepresented in these technology systems, so, for example, EMRs [electronic medical records]. If nursing work is not appropriately recognized and represented in these systems it can contribute to the under-valuing of nursing and the profession, and of course this can have negative implications for the recognition of nurses, for compensation of nurses, and so these systems really need to fully reflect the scope and complexity of nursing practice.

And then, of course, this also affects the quality of care for patients as well. I think a key understanding of digital health technology is that it can exacerbate inequity and it can result in more health data poverty. I think that’s a topic we’ll come to in a future question, but technology in itself is a source of inequity-generating interventions and so depending on how you want to split the digital divide, whether that’s age, geography, digital literacy, there’s many, many factors that make access and cost to technology an issue, for example, older adults that live in long-term care who may not have access to modern devices; Indigenous populations that may not have internet access, for example. So I think there’s a lot of issues when it comes to inequity.

And then the third is more general, but I think it’s the lack of user-centred design, so when we think about the technologies that surround us, and informatics systems, often they’re not created with the users in mind and the needs of the end users in mind, so this can result in systems that are difficult to use, time consuming. There are many consequences to that, so we can have burnout, moral distress. There’s a really wonderful article written by Atul Gawande in *The New Yorker* about “death by 1,000 clicks” speaking to the fact of EMR’s being poorly designed, so I think it’s a double-edged sword where we can have many, many benefits, of course, but I think we need to be aware of some of the perils as well. Maybe I’ll stop there.
ROSALIE: Well thank you, that’s a really comprehensive overview of a number of the issues. There’s just one thing I want to pick up on before we move on to another speaker, and that is when you were talking about the EMRs. I was really appreciative of your bringing to our attention Atul Gawande’s wonderful article as you mentioned, “death by 1,000 clicks.” But one of the things that I hear nurses talking, about particularly when new technologies are introduced, is a lack of time in terms of their understanding the technology and a lack of time in educating them about how they might use this technology effectively. And this has come up in particular in relation to EMRs, so not only in the development, yes, the nursing voice needs to be included, and nursing content, but also in terms of the implementation. I just wondered if you could say a couple words about that.

CHARLENE: I think that’s a great point. Many of these EMRs can be tailored to reflect nursing work, but sometimes young nurses aren’t at the table to be able to voice how that should be implemented or how it could potentially look. So because nurses make up the largest component of the health care workforce, as well as generate the most amount of health care data, it is really important for nurses to be at that table. And I think in one of the later questions we will talk about what are some of the roles of nursing and one of the roles is that of an implementer. So to me, I think being able to implement a system that can help support nurses in their workflows is really important, and it can have dire consequences if they are not supported in being able to use that effectively.

ROSALIE: Thank you. Elizabeth, do you have any thoughts about some of the promises and perils, or some of the issues that you think we haven't addressed to this point?

ELIZABETH: Thank you. Charlene, you gave an excellent overview of so many of the issues. The one thing that occurs to me right away is in five years from now, what will we be talking about is something that fascinates me greatly, so things are ever evolving.
The one thing though that comes to mind immediately, and I think this came up in class today, is that technology of course is wonderful, potentially, it can do many, many things, but there are also so many distractions in terms of fundamental nursing care. It worries me a bit if too much of our focus goes away from some of the fundamental things around having relationships with people—their dignity, care of the body, and all of those things that are absolutely important. Hopefully the technology frees nurses up to provide that kind of care to patients. I know that in some of the research, for instance with virtual visits, many clients in the home very much enjoy them in the sense that without them there would be no link at all to health care, but it still is not a substitute for a person being there physically. So it’s good, but there is always for me that piece of wanting to hold on to some really important things in nursing, and there ought not to be a complete distraction. So hopefully one frees up the other to make that possible.

Rosalie: Now those are some really great points. In my career as a nurse, who worked extensively as an advanced practice nurse in dialysis and transplantation, I saw that often when we introduced some new technology—because the focus became very much on the technology itself—and even though it was requiring that some of those technological artifacts, if you will, were used with the patient, the patient became lost in the application of the technology. So I think what you say is really important. Sorry—go ahead, Elizabeth.

Elizabeth: Just one quick thing, it just reminded me of the work of Margarete Sandelowski, who focused on making sure we nurse the patient and not the technology, so I had forgotten about her marvelous work on this.

Rosalie: That’s a great point to raise, and we will make sure we get a reference in to some of the work that she has done. Because the other piece of that, too, is the fact that particularly in regards to nursing ethics there’s quite a large focus on that relational practice and relational development, if you will, so we
want to be sure that we make that very clear that the technology is not who we're nursing, we're nursing the patient, so thank you for that. Paddy, is there anything that you wanted to add?

**PADDY:** Yes, maybe to ask a question as well. One of the things, as I’m thinking and listening to what you’ve said, and it’s been tremendous already in this time that we’ve had together, is about what questions are getting asked or aren’t getting asked, and how might we continue to promote the kind of forward thinking and insightful thinking that just came up in this last discussion between the three of you. What changes might we consider to help to move the human side of this forward more, not just paying it lip service, but really enacting it and really paying attention to those, for example older adults, who can’t even hear what we’re saying, let alone if we come in explaining a really complicated tech, for instance. So just your thoughts about how progressive change might happen that moves in a really strong ethical direction?

**ROSALIE:** Paddy, I’m wondering if we could hold on to that question, because we’re going to talk about that a little bit later on, and so perhaps we can come back, circle around, and come back to that if that’s OK. So Jan, what about you, is there anything that you wanted to add or any thoughts?

**JAN:** Well, you’ll all laugh at this, but when I knew what the topic was and thought, good grief, what do I know about that, and how did I get to know about that as a student? And what came to mind immediately was more of the classical technology like an iron lung. And in my training days I had a chance to help nurse somebody on an iron lung on the sixth floor of the University of Alberta Hospital, and as I thought about that, I thought what a way technology advances on us, and the knowledge to support a person even on the iron lung was pretty extensive, pretty intensive. Then I got busy, and I’ll not be long, but I was gathering books I had around here to just find those early days and one of them did actually—it’s a text that some of you will have heard of by Harmer, called *The Principles and...*
It’s very old, it’s very big. What I did find in there was a picture of an iron lung for the students to see lots of write-up about it.

I guess what other questions I would have is how do we get not only nurses who are in practice to be more conversant with these technologies and early learning, and how would we do that with students? So I’ll say more later if there’s time, but I have just had a very interesting romp through that. I guess the thing that finally came out in the end, is more recently, I’ve known friends with artificial hands, and this [shows photo] is a very good friend of mine, I don’t know if you can see, I think you can, you can see his hands, and he came to our wedding and he was delighted to be there. It was a big community hall, somebody came to tell me as the bride that he needed some-thing, and it was that he wanted to drink water, but with his clip the plastic glass disintegrated.

**Rosalie:** Technology—well, those are both really super examples of some of the things for many people—certainly the iron lung example—many people who will be watching this video will never had had the chance to have nursed somebody in an iron lung. I know there are only a few people left in the world who are still using iron lungs. It was so complex as far as some of the nursing care, the personal care that was required, and the relational care that was really necessary. So thank you for raising that.

So maybe what we can do is, based on just what you were saying, and what Paddy alluded to earlier, is move on to talking about, what do you think are some of the key skills needed to practice ethically, in these environments that we’re talking about where the development and use of technology is ever-increasing? So I’d be curious, maybe Elizabeth, you can start. What do you think some of the skills might be that we should be talking about in nursing and helping to develop?

**Elizabeth:** Oh goodness. I think, for one, we need critical thinking skills, in terms of students really understanding what kind of data is feeding into these kinds of systems. And
Charlene can speak to this better than I can. That it’s imperfect. And they need to understand that that data could be quite biased. It might not be relevant for certain populations. I think they need to understand that. Not to say that it’s useless, but to think about that critically. So that would be one thing.

I’d also want students and also leaders in practice environments to start to think about liability, if you will, in terms of responsibility. Who’s responsible, for perhaps, decisions being made? Where do we place that responsibility? So that’s something for many people to think about—regulators, as well, when these technologies become more prevalent. Those are some of the things that I would think about. A lot of critical thinking, I think, is important.

I really like what Charlene had to say. When these technologies are being introduced, to have nurses really have their perspectives given as to what is helpful, not helpful, in the practice environment. Having patients, clients also involved in the development of them so that they’re being used in a way that’s most meaningful and the least harmful, if you will, in very simplistic ethical terms.

**ROSALE:** Really great points, and it brings to mind, as well, technology assessment, which is quite a large area in health care and evaluation of technology, and even the development of the processes to do that. In many cases, nursing voices have not always been included. And so some of the parameters that have been considered in the evaluation have been missed, because there isn’t that nursing input. So I can think of a couple of examples in my own practice in the introduction of new equipment for dialysis, for example, where that’s occurred. And also I’ve heard recently from colleagues who are working in critical care, where new technology that was introduced there during COVID-19, there wasn’t always the opportunity to do the evaluation that was needed. And this increased nursing time and also impacted on the level of patient care that was able to be provided.
So thank you for those comments. Charlene, did you want to add anything to that, about some of the skills that you think are needed?

**Charlene:** Yes, so I recently authored a book chapter about this that was called the impact of digital technologies and new skills and knowledge that nurses need [The impact of digital technologies, data analytics and AI on nursing informatics: The new skills and knowledge nurses need for the 21st century].

**Rosalie:** Wonderful!

**Charlene:** So this is fitting. And so my co-authors and I, we looked at the basic roles of nurses, and nursing practice, and we reconceptualized core aspects of nursing practice. The five different areas were that of an advocate, an explainer, an implementer, a creator, and an analyst. Nurses have always been advocates for patients. So in this case, when it comes to digital health technologies, here we're talking about advocating for equity, advocating for access, thinking about the suitability of the technology to the patient population, thinking about social determinants of health, privacy, confidentiality, data ownership. And really being that advocate for that patient. And community, and population.

And then, the second, being an explainer. Nurses have always had the ethical duty to ensure basic principles of informed consent. Informed consent is being met, as a professional standard, and as a professional practice standard. And so, the same applies with technologies that people are using. When we're prescribing technologies for people to take home with them, they should know, “Where is this data being stored? Who has access to it? When can you look at it?”

Picking up on your earlier point there, Rosalie, about nurse as being an implementer, nurses have always led the way to move evidence into practice. And so this is the same for technologies as well. Using principles and frameworks for information science and implementation science, and to think about the context, the enablers, the barriers of moving technologies
into various health care environments, whether that be acute care or in the community.

Another role, and we’ve sort of touched on this several times now, but this is the core tenet of my own work, is that of co-creator. Again, nurses are the backbone of most health care systems. And so, because we are found in many different health care sectors, nurses have an in-depth knowledge about patients, about the illness trajectory, about the communities in which patients live, the clinical context, the workflow in many of these settings. And we are privileged to be able to see the care that is being delivered, where developers, engineers, and those who are outside of the health care system are not privy to [knowledge about this care].

So, this expertise is often ignored, and that is to the detriment of building successful technology, and implementation, and adoption of successful technology. So nurses really need to step forward, and make their narrative and expertise heard.

And then, lastly, picking up on Elizabeth’s point around the use of critical thinking when it comes to technology, I think the nurse as analyst, being able to analyze the vital signs of the patient up in front of you. Or if you’re a manager, understanding the data from your unit and making decisions around resource allocation [are important].

But I think nurses now, with the use of big data, and the availability of big data, we can take a more systems approach to think about broader institutions and future directions of where we need to focus our energy, focus different resources, as well as health human resources for the betterment of communities and populations. I’ll stop there.

**Rosalie:** Yes, some really excellent points that you’ve made there. I’m thinking that perhaps Paddy or Jan might want to make some comments, because you’ve raised a number of various points. I know that in other chapters of the book we’ve touched on this as well, in terms of nursing skill development when it comes to ethics. And it brings to mind also something we haven’t talked about so much, but the idea that if we look at
Patricia Benner’s work, for example, and look at that continuum from novice to expert, that there are different challenges in skill development at different levels of overall nursing development. So Paddy, or Jan, do you have anything you’d like to add?

**PADDY:** There’s so much to think about and talk about with both of you. This is marvellous territory that you’re in, and you’re embarking on, and that you’re critically analyzing. It occurred to me, too, that the way we educate nurses from the very beginning is going to be enormously important in fostering the kind of capability, Charlene, that you and Elizabeth have been talking about in terms of people who are critically questioning, people who are not too afraid of the tech, people who are able to deal with the intricacies of [technology] and so forth. And [these people are] *also* facing what has always been the case at the bedside, and that is the grief and the tragedy that some families and patients face, and how to support them at the same time as navigating a technological imperative. And I’d be curious to hear what your thoughts are about how to move forward in the future for that. I know it’s a complicated question, but I’m sitting thinking about both the human aspect of it as well as the technological expertise that’s required. That is a big commitment.

**ROSA莉:** And we’ll come back to that, certainly, talking about some of the future developments as we finish up this session. So thanks for your comments, Paddy. Jan?

**JAN:** I was just thinking, then, too, about not only how the caregivers get to know and understand what the new invention or the new lab technique will be, but just wondering about how those who have to think about budgets and paying for some of these very novel instruments. I’d be really curious to know who is looking at how those payment schemes will go ... with never enough dollars to go around. How will different areas be affected by their inability to fund some of these technical inventions? I know a few times we’ve lived through that.
It happens in the university hospital, and maybe five years later, six, it reaches some outpost nursing station. But the challenges are going to be greater, I think.

**Rosalie:** Well that’s a really significant point because we’ve seen how technologies that had in the past only been available in hospitals are now moving into homes. And certainly, again in dialysis, we’ve been doing very complex treatments for a number of years in patients’ homes. So patients themselves have been doing them, and their family members have been involved in helping in some instances. That’s just one example. I mean, intravenous therapies … There’s many things that were once just the purview of the nurse in a highly technological unit that are now moving into the community, and into homes, and into long-term care. And I know that’s something, Elizabeth, that you’ve given a lot of thought to and have been involved in thinking about in regard to home care, and the escalation of some of these things, and the skills needed by home care nurses to continue to provide that care. So you might have some thoughts about that.

**Elizabeth:** Oh yes, and no doubt there is a great escalation there, as in the hospital. The one challenge that home care nurses have, not only with respect to new technologies and so on, but just in general, is that they are often working alone. So some of the learning opportunities that one would have in a hospital situation might not be as readily available. Again, you have to think about educating the clients at home—they’re often older adults. Many of them are very comfortable with technology, but some are not. And when technology goes awry, again, in the home it can be more of a challenge, as it is for any of us when we have problems at home. To get someone in to repair, help, intervene, and so on can be easier in a hospital, because it is more [accessible]. But some of these [technological] things, yes, in the home, can revolutionize things.

With the other end of the spectrum, though, in terms of still respecting people’s privacy, where we have people being monitored for a number of things, for their own safety,
perhaps for vital signs, but it can be much greater than that, what the monitoring can entail. So the privacy aspect is really important to think about, particularly more on the extreme end, when we start to monitor people, especially in their own homes, where they have a high assumption around privacy. That would be probably the most private place to most people, where they live and go to sleep, if they live in a home, an apartment, etcetera. So privacy is a big one that we need to think about. And engaging again, that population, in terms of education, and what’s okay? We need their input.

**Rosalie:** Charlene, anything that you wanted to add to that?

**Charlene:** We have a couple of projects that are focused on technologies for the home and designing homes and sensor systems to help support older adults living at home. It’s a really interesting kind of area to explore, because there’s so many ethical issues when it comes to using sensor technologies in the home. The capabilities of sensors these days can detect the quality of sleep, how fast you’re breathing, your heartbeat, how many times you leave the house, how fast you’re walking, where you drive! The proximity of you to, perhaps, your loved one. How long you’re spending together. And so there’s many inferences somebody can make based on the data and being able to triangulate the data around somebody.

But there’s several ethical issues when it comes to using this. Often, and I know from talking about this from a health care perspective, [there is] a health care provider potentially making the home more of a hospital kind of setting where you have these technologies in that home, but there’s that presence of a health care professional. But in many of these cases, and in my own life personally, I’ve had so many people ask me about putting in these monitors and going to Best Buy and buying these home sensor systems for their parents. And so now you have family caregivers who are also using these technologies, and they’re not fully aware of what to do with the data. When is something important, when is something not important? And then their parent, on the other hand, who is being monitored,
also doesn’t understand what can my daughter/son see? How much are they actually following me here? And so what could be interpreted as, “Now all of a sudden I can’t live by myself anymore?” So there is this instilment of fear. What’s going to happen if I fall now? So it raises some really interesting questions around boundaries, changing of dynamics, changing of relationships. It really changes the nature of different relationships, not just between nurses and patients, but also family members, as well, that are part of that care team.

**Rosalie:** Yes. You’ve brought up a number of really important points there. I was just thinking about recently, a situation—well, it wasn’t too long ago—that I was involved in, where I was talking with a parent of someone who has just switched to a continuous glucose monitor, which has been revolutionary in terms of diabetes care. No question, people get real-time data, fewer finger pricks—so many advantages. But they can also share that data with other people. So what’s happened in the case that the family member, the parent, was telling me about, is she now receives the data from the glucose monitor, and she is now feeling like she’s responsible to deal with the data she receives. Yet her teenager would prefer her not to be involved in that. So that’s the other piece of it. If you have data, what do you do with it? And how do you work with it? And where does that line fall between autonomy and also people who think paternalistically that they ought to be intervening? So you’ve touched on some of those important points, for sure.

So before we leave this area about skills needed, I wondered if we could just have a couple of minutes of conversation about whether you think there are some specific skills that are needed by advanced practice nurses or advanced practice nurse leaders, because many of the people who are going to be watching this video and reading this book, *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice*, are going to be advanced practice nurse leaders. So could we just maybe hear from you, Elizabeth, about what you think might be some of the skills that those advanced practice nurse leaders might need?
ELIZABETH: Well, the first thing that comes to mind is many of them are educators, in various contexts. So they are going to need to become very knowledgeable about many of these things—to keep on top of this, to be able to use these technologies, and then to be able to teach about them. So knowledge, I think, is going to be absolutely huge for that group of nurses. So this would be one of the really key things that comes to mind for me immediately. Charlene and others may have some other ideas from other types of advanced practice nurses because there are many different kinds.

ROSALIE: Right. Well, that’s a really significant one, and you’re right, a number of nurse educators will in fact be watching this video. And within the book, we have a chapter about some of the ethical issues related to nursing education.

Charlene, what about you? Any thoughts about advanced practice nurse leaders?

CHARLENE: Yes, it’s a great question. APNs are such an important part of the bigger picture when it comes to digital technologies and the implementation, the co-creation. And from my perspective, technologies are really a critical enabler of APNs.

And if you look at the advanced practice nursing pan-Canadian framework from the CNA, the competencies include direct comprehensive care, optimizing health system competencies, educational competency, research competencies. All of those are supported by technologies, and so when you look at the individual sub-competencies under these categories, for example, optimizing health system competencies—one of the sub-competencies is being able to generate and incorporate new nursing knowledge, and to develop standards of care. Well, if you have technology you can look at the data and be able to help generate that knowledge to support any standard of care. So all of the different competencies are supported if we can actually look to the technology and embrace it and be able to understand it using critical thinking and being able to have a broader appreciation of the data that is being collected.
ROSALE: Well said. I know in my own professional career when working as a clinical ethicist, many of the referrals that I received about ethical challenges came from advanced practice nurse leaders, and some of them were related to just what you talked about, and [often] the nurses didn’t believe they had the skills to be able to even provide that guidance and support and also leadership that was needed in those areas. So I’m glad to hear you bringing us back to the competencies. That’s great. Sorry, go ahead Charlene.

ELIZABETH: No, it was me, actually. One thing that also came to mind, Rosalie, is that competencies, obviously, are really important, in terms of skill development, nurse practicing, and so on. But the one thing that I would be mindful of is it’s not just the “what we know and how we do it,” it’s also who we are. So the moral identity of nurses is really important here. Nurse leaders often set the stage for that, for that moral behaviour to be part of our identity alongside with the competencies and so on. Again, I always go back to distractions. And what is the distraction of the day, if you will. And that’s one of them, is that we tend to throw out too many things when we adopt new things. So competencies, yes. But who we are, I think, is something also that advanced practice nurses have a big role to play in maintaining.

ROSALE: Excellent point. Really excellent point. And that ties in to what we’ve been talking about around relational practice as well. And the “who we are” is so important in that, for sure. And Paddy, I know that’s an area that you’re particularly interested in. So do you have any points that you’d like to add?

PADDY: Yes, just to say the whole discussion has been wonderful and enlightening. And Charlene and Elizabeth, we’re really blessed to have your expertise here. And I know that Jan, Rosalie, the backgrounds everybody brings to this is so important.
And having done critical care, which was fairly high tech back then—this was a few decades ago—certainly it was easy to get caught up or distracted in the mechanics, the pathophysiology, how somebody’s blood pressure is doing, and so on. That certainly was important material, and something that we had to pay attention to, but the harder questions even then, in what was then a fairly highly technological environment for its day and age, was also about “How’s the family doing? How’s the team doing? What does the family understand about whether this loved one will get better or how they might proceed? How are we coaching them to help them with their grief? What resources do they have?”

And I would also add, the other thing we’ve learned about—and of course this is where the concept of moral distress has been completely invaluable—is to understand “How are the care providers being affected? How are they working together as a team?” And I think again, as I’ve listened to each of you, that those kinds of questions are flourishing in the kind of work that you’re talking about and doing.

I’m certainly not anti-technology, although I’ll never brag about being particularly good at it, but the danger in technology is that it can distract us away from some of those really deep human conundrums that walk into our hospitals, and that walk out of our hospitals, where we hope that they’ll get home care and other resources. Again, I just think that the insights that you’re bringing to this are so important. So thanks for a chance to talk about that.

Rosalie: Thanks, Paddy. Some really important points that you’ve raised there, and things that we need to think about, always. And it goes back to some of the earlier points you made, Charlene, about the promises and perils, so I think that’s a really relevant set of points that you’ve brought us back to think about, Paddy. Thank you.

And Jan, anything that you wanted to add before we move on to talking a little bit more about data and research ethics?
JAN: I don’t think so, Rosalie. I think some of the main areas have been touched on. Going into depth on any one of them would be [interesting], but I would like to hear the “what’s next” that you’re pointing to. I think that’s most important.

ROSALIE: Thank you, Jan. So, in terms of thinking about, you know we’ve tossed around terms here so far—big data, and we haven’t really talked about it, but we’ve used the term AI—artificial intelligence, and we mentioned research ethics. But I think what I’m curious about, and I think what all of us would benefit from hearing more about, is what do you think some of the implications are for data disparity, and even pernicious bias, for example, for ethical clinical practice, particularly as it might relate to ethical conduct of research? And I know, Elizabeth, you’ve been involved in a number of activities in this area, so perhaps you might like to start.

ELIZABETH: Well, one of the things I think that has been a part of conversation is for researchers to really have a strong understanding of the databases they’re using, and what their limitations are. Because there are always limitations. Because once those data sets get put together, what are the outcomes that people are going to look at? Is this reliable, what is coming forward?—is one of the things that is strongly emphasized.

The other thing, however, is it may seem lacking in risk, to use data where there is no contact per se with participants, but some of the ethical issues actually arise upon dissemination, and not so much in those early stages. So someone is bringing together data sets that may have implications for groups in society, especially if they are based on things like race, or on socio-demographics, and so on. Those implications can be huge. And so, some upfront thinking needs to go into this with community engagement, and so on, to make sure communities are involved in the kinds of research questions that are being asked. But really important, to make sure they’re involved in dissemination, in order to avoid some of the stigma and naive kinds of conclusions, and sometimes very painful conclusions for groups, if they’re misunderstood.
Especially if the data is imperfect, and all data *is* imperfect. So that is something that research ethics I know currently is really looking at, is that point of dissemination, as well, and community engagement.

**Rosalie:** Well, thank you for raising those points, and I know that, in particular, there have been a number of challenges in those areas with Indigenous communities, both around collection of data, data ownership, dissemination, and I think what you bring up applies, certainly, to that community, but also to many other communities as well. So thank you for raising those points.

Charlene, did you want to add anything to that?

**Charlene:** Data disparity is a big issue when it comes to technology and the collection of data. We live in a digital world, and we have 2.5 quintillion bytes of data, I think, that are being collected every single day. With all of that data being collected and knowing that data is being used to build and train different algorithms that impact our day-to-day lives, it’s really important for us to think about “whose data is that?” And who is being left out of that data? And so when we talk about health data disparities, there’s an article that was in *The Lancet* that was by Ibrahim, I think, in 2021, and they define health data disparities as systematic differences in either the quality, or the quantity, or both, of health data that represents either different individuals, groups, or populations. And so that can be across demographics, disciplines, or diseases.

And so when you have these health data disparities, that results in health data poverty, which is defined as groups, or individuals, or populations that are not able to benefit from the discovery or innovations because they are not being represented. And so when we think about this at a global scale, in high-, middle-, low-income countries, it’s likely that you’re going to be leaving out a lot of people in low-middle-income countries—that don’t have the technological infrastructure, that don’t have the access to use advanced technologies that are quite sophisticated on a day-to-day basis, may not even...
have the infrastructure, as in the internet, to be able to use some of these devices. And so then we may end up exacerbating different inequity gaps between have and have-nots.

So I think we really need to be cognizant that these datasets, like Elizabeth had mentioned here are not perfect. They underrepresent key segments of the overall population. And this data is being used to design digital health technologies that will be safe and effective for some, but maybe not as effective for others. And I think there’s a lot of examples of that in the literature.

**Rosalie:** I appreciate what you’re saying about some of the global injustices because those are not questions that we often reflect on, or certainly not for very long, anyway, and I think it’s important for us to think more about that. Sorry, go ahead, Charlene.

**Charlene:** I was just going to say, clinically, I think there was an example in 2019 by Thomasev, where they came up with an algorithm in order to predict acute kidney injury in adults. But in their dataset, they only had 6% who were women. So, of course, the algorithm was not as effective in women as it was in men. That’s just an example of how you would have gender-related health data disparities that then end up causing relative health data poverty in women.

And then even more recently, with COVID-19, the *New England Journal of Medicine*, as well as the *British Medical Journal*, they had reports about pulse oximeters. And pulse oximeters don’t work as well on darker skin, because they are calibrated on people with white skin, and so now we have—I think their study said that pulse oximetry readings missed three times as many cases of hypoxemia in Black patients in comparison to White patients. So said in another way, it’s not detecting hypoxemia to the rate of three times for people with darker skin, which means that nurses may not be able to properly triage patients. This is a significant issue in COVID-19, which causes acute respiratory distress, and [nurses may not] apply critical supplemental oxygen in time. So there’s a lot of clinical examples when it comes to data disparity—harm from
algorithmic bias—and so there needs to be a lot more consideration and attention to this, for sure.

**Rosalie:** Well great points, and I’m just going to ask Paddy to comment on this for a moment because I know that disparity has been relevant and evident in some of the work done in cardiac care, where women, for example, have not been included, or people from different ethnocultural communities, or socio-economic groups. And Paddy, I know that that’s an area of interest of yours, so do you have anything that you would like to add?

**Paddy:** Thank you. I guess a lot of what I’ve been posing are questions, because the information you’ve given us is so powerful. It makes me wonder, listening to what you said so eloquently, Charlene, we talked earlier, and Rosalie, you emphasized the importance of being relational, that is, respect, looking at how we’re situated, how we work together, and so forth. And I was thinking that there needs to be a heavy dose of relationality to go to some policymakers, some scientists, who are obviously incredibly well meaning, but aren’t perhaps asking the right questions, and may not have been going through either educational [systems] or organizational [systems] where they’re rewarded for that kind of question asking. Because again, Charlene, listening to you, the kinds of points that you’ve raised, and that you’ve raised, Elizabeth, help us to dig beyond the surface in order to be closer to get to what’s actually going to make a difference in people’s lives. So I really want to thank you for that. I just think it’s enormously important, thank you.

**Rosalie:** Thanks, Paddy. And Jan, I know that in your career, research ethics has been very prominent. And you’ve been very involved in a variety of different research ethics committees and groups. Reflecting on some of these questions, is there anything that you want to add?
Jan: I want to thank you two so much for the light you’ve shed in various corners of this topic. I think you had so much to add to it, and so many things to say about the goods, the bads, and maybe the ugly, and that is very meaningful, and very important for the rest of us to hear and know. I think especially some of the challenges of home care. In Montreal for a couple of years I was a home care nurse—[home care] was just in infancy in some ways for what could happen and how I could care for people in a way I wanted to. So I think both the home and the hospitals, and long-term care areas, long-term care homes especially, I think, so at risk, many times, for what’s happening. We need all of [your] advice, and we need to find a way to spread it around in whatever way we can. I thank you both so much for coming, and being part of this discussion.

Rosalie: Thanks for your comments, Jan. One of the things, before we wrap up and talk about the [nursing] roles and some of the future thinking that we might have about areas where we can continue to develop and improve—and where we can make changes in what we think about nursing ethics—I just want to give you, Elizabeth and Charlene, the opportunity to say something if you wish, about big data or research ethics. You’ve touched on a number of points, so don’t feel like there’s anything you have to add, but I don’t want to move on to the next section until I’m sure that you’ve covered all the areas you want to.

Charlene: Maybe if I can add one more mention of bias. I think I gave an example of gender-related bias, and race-related bias. My work in particular is examining age-related bias, so I look at digital ageism and the ways in which ageism, which is an implicit bias, is then entrenched in the way we ideate technology, develop technology, build technology, and implement and then evaluate technology. And so in some of the work that we’ve done, we examined seven of the most commonly used publicly available facial data image datasets. These are datasets that contain hundreds of thousands of pictures of people that are taken from the internet. And these
datasets are used for facial recognition, age estimation, and other AI applications. And when we looked at the seven most commonly used facial datasets, we found that of datasets that had tens of thousands of images, many of them had less than one percent of pictures of older adults.

So the implications of that, and speaking just more broadly around data disparities and not being able to benefit as much from the technologies that are being built, I think are really applicable to age tech or gerontology or technologies that are being built for older adults. I think that’s a really important piece that we don’t necessarily focus on when we talk about bias in AI. We tend to talk about it with respect to gender and race, but not so much with age, and a lot of my work is trying to shine a light on that—just broaden the aperture a bit.

And then Jan, you mentioned the different settings, but you know I think we’ve spoken about acute care, we’ve spoken about home care, and long-term care has come up a bit, but I think long-term care in particular—again, a place of older bodies, staffed by racialized women. I think it’s a really interesting cross-section of society, and certainly the way that technology is experienced is very different in a setting like long-term care. And so, in the case of COVID-19, where long-term care homes were in lockdown, and residents were not able to see their families, and families were not able to see their loved ones, they became these total institutions where the only way to have any contact was through technology, and a lot of them did not have the infrastructure to even support an iPad, or have the staff to use the technology in place. I think this speaks to sort of the broader context of how technology can change the nature of nursing work.

And so when technology, for example—and I think Paddy had mentioned the idea of grief—so over COVID-19, we had protected Code Blues. I mean I know in nursing school we never ran Code Blues using baby monitors, right? Like, that’s not something that anybody knew how to do from nursing school. But come COVID-19, that’s what my colleagues had to do. We were running Code Blues in ER using baby monitors. And people were saying goodbye to loved ones using iPads in...
the ICUs. And in long-term care, people were trying to have conversations using FaceTime, with not-so-good Wi-Fi. And so it really changed the nature of how we care, the way we care, the nature of care.

And so I think these are really big important ethical issues that deserve examination. And I think we need to be sort of raising these questions within nursing curricula. There’s some nods to how we prepare our APNs and the future generations of nurses to be sort of stewards of technology, but I think we need to be raising some of these really important questions earlier.

**ROSALIE:** Thank you, Charlene. Some really significant points. And Elizabeth, anything you wanted to add?

**ELIZABETH:** One point. Also with respect to long-term care and home care. There is a very large group of unregulated workers in that area. And these people also need to be very much involved in the development of technologies. Even much more than nurses, they don’t have a seat at the table. And, they are often the biggest point of care for older adults and other people who live in these settings. So, I’m basically just advocating for that group not to be forgotten.

**ROSALIE:** Well, thank you for raising that. One of the things that throughout our book, and definitely in this discussion, that we want to be clear about, is that [even though] what we’re talking about may relate to nurses. But it is our actions that we have with teams and other health care providers, that are equally important in terms of ensuring that patients and families and communities get the best care possible. So I appreciate what you’re saying, and thank you too, Charlene, for raising some of the issues that COVID just made much, much more apparent, and much worse.

And it’s probably a good segue into the last section that we wanted to talk about today, which is to think about what roles nurses have in future developments, as they relate to digital health technologies, and other technologies. And we’re being faced on a day-to-day basis with an array of different
technologies that are being introduced without a lot of consideration about the impacts, and certainly the ethical issues that they might present.

And one of them, that some of us were talking about recently, is this whole area of bots that are being used, like ChatGPT, for example. And I was just made aware recently, that although that technology has been in development for a while, it was just introduced in November of 2022. And while we’re doing this session, it’s just a few months past that, and there’s already a hundred million users. And so, what are the implications of that technology? And it’s just one form of technology that has recently been introduced and has implications for health, for education, and a number of areas. So the question I would really love for us to address for a few minutes is, what role do you think nurses have in the development and application of health technologies to make sure, or to ensure, that these new technologies are developed and applied in accordance with ethical standards?

And maybe I’ll start with you Elizabeth, because you and I were having some discussion about ChatGPT, for example.

ELIZABETH: Gosh. Well, to your first question, when I think of nurses and ethics, for example, many of us have a hybrid background. It’s very, very common for people in ethics to have a variety of backgrounds, philosophy, nursing, and so on. I think if we could promote nurses also gaining quite a solid education, perhaps in engineering, computer science and so on, we could develop a cadre of nurse innovators, scientists, leaders, [with] a very untraditional hybrid background. Much in the way as has happened in bioethics. A lot of people in bioethics are hybrids, as I call us. And so I can see the same thing being really hugely beneficial in nursing with respect to these technologies as well. I know Charlene has a lot of expertise, which I could never claim to have in these areas, and probably has something to say about this as well.
**Rosalie:** Thank you, Elizabeth. That’s an important point that you raise, I think, and really relevant to this discussion for certain. So Charlene, what are some of your thoughts?

**Charlene:** I think some of the roles that nurses could have within technology, are as innovators—I think nurses have always been very resourceful individuals, and nurses have a strong idea about what the problem is, and what our potential is to solve a problem. So I think nurses have a lot of ideas. And so, having the wherewithal to advocate for some of those solutions and work collaboratively with others as innovators, I think is a really big role.

As I’ve kind of been banging the drum, I think nurses are co-creators. I think alongside coming up with some of the ideas, nurses also make space for patients and patients’ families, and staff—that narrative of the patient, the patient’s story, in person-centred care, and the humanistic aspect of technology to make sure that technology is reflective of the needs and wants of the user, is embedded into the technology itself.

So not only from a data perspective, but I mean from a hardware perspective, like is the data easy for the user to use? Can somebody actually implement this and use this on a daily basis in their lives? Does this make your life better? And so really asking some of those questions and being that person who can help support and educate, I think is something that nurses can do really, really well! And then also from an implementation perspective, I think nurses, again, move evidence, move innovation into practice. At one point in time the stethoscope was considered technology, and nurses were the ones that wore the stethoscope and used the stethoscope on patients’ bodies, and I don’t see this as any different. I think there are many, many significant roles that nurses have.

Where we don’t prepare them enough is in our curriculum, because it doesn’t have—in my own perspective—we don’t emphasize informatics and health technologies and digital health technologies enough in [the] curriculum, so that nurses can be prepared to ask some of these bigger questions that are related to advocacy, that are related to education, that are
related to creation, implementation. And then going back to some of the things that we talked about—the changing nature of nursing work. So being aware of those things. How do you advocate to make sure that there is that humanistic touch? And to make sure that technology is not being introduced as a straw man? And it's not being introduced as a Band-Aid solution?—so that the underlying issue, that may be a lack of nurses, is addressed appropriately. I think in one example that we’ve spoken about in the past was a robot greeting or doing assessments in waiting rooms, because the wait times and the hours are ten hours plus, and so there’s a robot going around doing that now. So I think we really need to be aware of the reality that technology is being introduced into, as well as nursing practice. And I think nurses *are* the voice of the patients, and of the families.

**ROSALE:** Really significant points. And I’m thinking, as we come close to closing, one of the things that I’d be interested in hearing a bit more about, and I know my colleagues that are part of this discussion would be as well, is more about the implications, the ethical implications of some of these programs like ChatGPT, for example, on educators. Because a number of the people who will be looking at this video, and reading this book, will be nurse educators. So I just wondered, Charlene, if you could say more about that, because I know you’ve given it a little bit of thought, and might have some insights that you would like to share.

**CHARLENE:** Sure. ChatGPT has taken the world by storm, and so I think almost every higher education institute, at the moment, around the world, is talking about ChatGPT. But I think there are significant concerns around ChatGPT being used for plagiarism, and how it can impact academic integrity, but also can get at the heart of key practices that help develop critical thinking. So, I think a good example is being able to articulate ideas, and writing ideas, and synthesizing ideas. But you can put those ideas into ChatGPT or you can cite different articles, and ChatGPT can synthesize it for you. And you can even
identify what reference style you want it to be in, and it can provide you with the references, in that reference style.

ChatGPT though, is not perfect, so I think as educators we need to be aware of how to use ChatGPT. I don’t think it’s something that we can ignore, that it’s something we can turn our backs to. I think that it’s almost something that we need to embrace. So, potentially, when we pose a question to students, we are using, we generate something from ChatGPT and actually provide it to them, and say, “validate this,” or “how would you improve upon this?” So have ChatGPT do the basics, and expect more from our students to think a bit more critically around what’s being produced, or what’s being given to them.

I think, also this calls for educators to think about different assignments that require scaffolding in class, so that students can show that generative work over time. And so I think this is an opportunity to rethink some of our approaches, especially when it comes to nursing education.

One story that I will share about ChatGPT was I typed in a question about nursing informatics, and it actually provided me points from the chapter that I had authored. And so then I typed in the same prompt again, and I said, “Provide me references,” and so it provided the same prompts but now at the end of each sentence it actually provided me a reference, so it said Chu et al., 2021, and at the very end where it would provide me with the actual full text citation in APA style, it actually made up a completely imaginary reference. So it said my name, it said authors that I had co-authored with, a year. It made up a title, but actually cited a real journal, provided a volume, an issue, page numbers. And so I thought to myself, you know what, I’m going to see what is actually in this journal when I look up the citation, and it had nothing to do with informatics, or technology, or me, or any of my co-authors. It was from a totally random topic about nursing.

And so we really need to be careful around how we are using this type of technology. It’s not perfect, and so students really need to be aware of that. But ChatGPT—sorry to keep going on about this—ChatGPT also has implications for
health care, because a lot of people are actually using ChatGPT as a counsellor. So somebody can type in a question around how “I’m feeling down today, what are some things that I can do, what are some things in the area that I can do to raise my spirits?” And it will provide you a really detailed example or really detailed answer about what someone can do. So people are actually turning to it for mental health issues and it’s actually being used in mental health care virtually. It has some interesting implications, for sure.

**ROSA Lie:** Well thank you for that, I think you’ve given a nice overview of what some of the pitfalls are, but also what some of the promises are, because I think one of the points that you’ve made that’s really important in this whole discussion is for us not to take an adversarial approach to technology. It is with us, it is here, it’s always been involved in the development of different interventions within nursing, from the development of the thermometer. All of these areas we’ve talked about today, we can see how things have progressed. So, it’s important for us to be cognizant of that, but to understand where we need, as nurses, to be involved, and to make sure that we’re doing the kind of critical thinking that, Elizabeth, you pointed to earlier, and that we’re involved with application and also with the development and implementation. So those are really significant points.

I think we’re coming close to the end of our time. I know we can continue to talk about all of these areas for a long time. I wanted to ask if each of you could, perhaps, make a final point that you either think we haven’t covered, or it’s a message that you want to leave people with. And try and make that a pithy point, which is not always easy. So why I don’t I start with you, Paddy?

**PADDY:** I’m chuckling, because I was just thinking about, now what would be a pithy point? Well, I think the whole session, I just can’t thank you both enough, and the insights, and the wisdom, and the mutual support. I think it also shows the relational nature of our work. We learn from, with, and about each other,
and how we take those insights forward. And I think it’s incredibly important when we’re into high tech and high stakes areas, such as the development of the kind of technology that you so eloquently described, Charlene, particularly the example of running into it as well, and seeing what happens. So I think it shows that we have a great deal to learn, we have a great deal to contribute, and we do it best I think when we work with each other across disciplines, within nursing, and so forth. So that was just a long-winded thank you.

**Rosalie:** Thanks, Paddy. That’s a really significant point. And Jan—what about you? Is there something that you would like to leave the listeners with here today?

**Jan:** I want to say just how much I appreciated this time. The things I’ve learned during this time. I think what concerns me is how can we get more access to this kind of understanding, first of all. And technology, and what can be done? And especially, I think of people, again, who are maybe in home care, alone at home, people looking after their partners and that. But more than that, people who need to know what is possibly available in terms of information they could find out about. And it seems to me that some of what you’ve described is absolutely amazing, and wonderful to consider about how that could be helpful. And I’m just hoping there is going to be a way to get that information more locally to people who need it the most. How they can have access, what they can do to help themselves, in a way? So that’s my parting thoughts, because it’s such a rapidly developing area. I think the challenge for nurses, if we put [technology in the hands] of nurses, is to not be afraid to learn about it, and to be bold in using it.

**Rosalie:** Well, really important, Jan, because as you say, we want to make sure that we try and level the playing field, and that there aren’t these inequities in terms of who has access to knowledge, and who has access to the technologies, etcetera. And that we emphasize this within nursing, and ensure that
nurses are getting the education and the support they need to stay involved and to be current, and to also be innovators and change agents. I appreciate your comments. So Charlene, what about you, any pithy last comments you would like to make?

**Charlene:** I think I just want to thank the three of you for your invitation. I’ve really enjoyed this time that we’ve spent together, and it’s been really informative for me, and I hope it will be informative for the viewers in the future. My last ending message is nurses are a really, really important part of this picture, and there are ethical issues all along the technology pipeline. Nurses need to make their voices heard, from ideation, to implementation, to evaluation. I know that some nurses might not feel comfortable in any of those different aspects along the pipeline, but nurses are advocates, and I think we can be [people] who can put a small light on some of these really important ethical issues. So thank you again.

**Rosalie:** Thanks, Charlene. And Elizabeth?

**Elizabeth:** One pithy point, building on Charlene’s last point. I think we really, really need to hear from point-of-care nurses, in every context. In terms of evaluating technology, to development of technology, and so on. But we won’t hear from them if they’re not freed up from their caregiving responsibilities. So maybe this is more of a message for nurse leaders or others in organizations, to free nurses up to be involved in these kinds of activities. Otherwise, we won’t hear from them, because they’re so busy providing care, and so on. So it’s more of a message of “please consider freeing them up to be involved in this really important activity.” Along with all kinds of other activities that they’re not free to be involved in. So that would be my biggest message for APNs, who may have some control over nurses’ work. So that would be my pithy point. And also, thank you very much for inviting me. I’ve learned a lot from everybody in this group, so thank you. And it’s a wonderful book. I’m using it in my course, and I’m glad that there is an addition to [the book] involving technology.
**Rosalie:** Well, thank you, Elizabeth, and you’re a big contributor to that book, and have been over time. It’s wonderful to have you now, Charlene, as well, making these contributions. As has been already said, I do want to extend my thanks to you [both], and to Jan, and to Paddy, for this session. I think we could continue this conversation for a long time, for sure. But lots of messages for people to think about. I’ve used this book, the previous editions, in teaching ethics courses at UVic at the graduate level, and I know that other people have done so as well, across Canada, and in other places in the world.

And I think one of the things that I really want to leave people thinking about is that we have a lot of information, as you mentioned, Charlene, earlier, in terms of the number of terabytes, I’ve forgotten how many you said—What was it again?

**Charlene:** A quintillion.

**Rosalie:** Yes. So there you go. And a lot of what we know about this area is evolving rapidly, for sure. And we’ve got a lot of literature out there. I’m a very big science fiction fan, as I know others are in this session. But we can learn from mistakes, too, that we’ve seen in literature, in studies, in what’s been written. And I think we need to take that up as well, as we reflect on where we go in the future, and make very careful choices in terms of implementation. Just because we have a technology, doesn’t mean we ought to use it. And so I think that’s the other piece that we have to be very careful about. Because it’s often considered that something that’s new and innovative means it’s better, and that may not necessarily be the case. So we have to move with prudence, and with careful, critical reflection.

And then lastly, I just wanted to say that, in terms of some of the technologies that we haven’t talked about today, that are worrisome—big data, or artificial intelligence, or perhaps even the use of robotics, etcetera. [These] are areas where hopefully the viewers and readers of this session might want to explore a little bit more in some of their work. Because, again, there’s many, many promises, and we’ve seen the benefits of technology, but we also want to be cautious about the perils.
So that’s the challenge that I throw out to everybody, to become as fully aware as you can. And, in aid of that, what we’ll do at the end of this session, is to add a number of references that will be useful for people to consider. We’re also going to be adding this video as a transcript to the overall digital book that we’re writing. The transcript will include some references as well. So that will give people an opportunity to view, listen, and read, so that will be accessible for, hopefully, everyone.

So with that, thank you very much again, and I’ll look forward to us as colleagues continuing these discussions, and maybe even doing some more writing about this in the future. So I wish everyone the best. And also, just to [let viewers know], I think [we will] include email addresses, if that’s acceptable to you, Charlene and Elizabeth, and I’ll talk more with Paddy and Jan about that. Because students and readers might want to connect with you in some way after this. So we’ll talk about how best to provide that information.

**PADDY:** And just before we close, Rosalie, I wanted to provide a huge thanks to you for helping to organize and guide this session. I think it’s gone incredibly well, and it’s been a vision. I know it’s a shared vision with all of us, but I think you’ve really understood what the necessity and the opportunities are here, so thank you so much for that.

**ROSALIE:** Well, that’s lovely for you to say, Paddy, thank you, and I’ve enjoyed this immensely. It’s hard to say that we have to close, but we do. So, I look forward to future discussions. Thanks very much, everyone.
Endnotes

1 “We now have a new protocol called a Protected Code Blue. A regular code blue is an emergency, when someone is in cardio-pulmonary arrest. They announce it over the speakers. In normal times, it’s all hands on deck: there are lots of people in the room, running in and out to coordinate and deliver medication and care. Now, whenever there’s someone who’s really, really sick, and we announce a Protected Code Blue, there’s almost no one in the room with them. We assume they have COVID-19. You just don’t know, so we’re trying to maximize precautions and not get inadvertently exposed to the virus. Lots of us are outside the room where we’d normally be in it. Just last night, we had a patient who came in sick and we called a Protected Code Blue. I communicated with the team inside—a doctor and two nurses—using a baby monitor, on the other side of the door. I can’t imagine what it’s like for the doctor in the room. You feel so alone as you’re resuscitating this patient. I’m there on the other side of the glass, giving advice into a baby monitor. It’s not the way we’re trained to do this job” (Choi, 2020, para. 5).

References


AS THE 21ST CENTURY UNFOLDS, society is in the midst of a profound revolution in biotechnology—a revolution that is radically altering our view of who we are as human beings, as well as our conceptions of health and health care (Lee, 2016; Nuffield Council of Bioethics, 2012; Stevens, 2016; Susumu, 2011). The seeds of this revolution were planted when Canadians Frederick Banting and Charles Best first discovered insulin for the treatment of diabetes in 1921, thereby launching the field of biotechnology. Since Watson and Crick’s historic discovery of the double helix of DNA in 1953
remarkable strides have been made in biotechnology, and in the last few decades, the “biotech” industry has emerged as the cutting-edge industry of this century. The identification of the human genome, and the breakthroughs that have arisen in the world of genetics, have resulted in significant changes regarding conceptions about disease and disability. In addition, society is faced with a myriad of new health care technologies emerging from research in areas such as artificial intelligence (AI), genetics, human reproduction, nanotechnology, regenerative medicine, robotics, and xenotransplantation (Association for the Advancement of Blood and Technologies, 2023; Anjum et al., 2021; Daar, 2002; Hobson, 2016; Holland et al., 2001; Hovatta et al., 2010; Jarry, 2022; Kaul et al., 2020; Mnyusiwalla, 2003; Skloot, 2010). The implications of this biotechnological reframing are vast. Today, developments are occurring at such a rapid rate that there is often insufficient societal discussion about the ethical and social implications of the scientific advancements being made. Further, this rapidly expanding evolution of diverse forms of biotechnology is having an increasingly profound effect on health care delivery, including nursing practice.

Science fiction writers have for a long time shed light on some of the value conflicts that can be generated by technological developments. Sometimes it appears that, as a society, we are prepared “to boldly go where no one has gone before” (as described in the Star Trek science fiction television programs, movies, and books), often with minimal critique of the direction in which we are moving. However, whereas Star Trek provided opportunities for the show’s writers and actors to examine the moral dimensions of featured technological “wonders,” as a society, we have not always reviewed the social and ethical consequences of biotechnological developments prior to their implementation (Midgely, 2000; Rappert, 2008). Thus, the diffusion of biotechnology into the health care system continues in many situations without the thoughtful reflection that is needed.

My goal in this chapter is to consider the ethical and societal challenges that are often pushed to the margins as we “boldly go where no one has gone before” by discussing xenotransplantation as an exemplar of biotechnological development. Xenotrans-
plantation, the transfer of living cells, tissues, or organs from one species to another for medical purposes, has arisen as one solution to increase the number of organs available for transplantation (Carrier et al., 2022; Fischer & Schneike, 2022). Many of the issues, concerns, and troublesome questions that emerge about whether xenotransplantation should be part of the therapeutic armamentarium to treat end-stage organ failure are also evident in other domains of biotechnological development. In what follows, I offer approaches to advancing dialogue and debate about the ethical and societal concerns that are emerging as part of the discussion about the development of xenotransplantation, particularly strategies to enhance nursing leadership in the area. I also illustrate what advanced practice nurse leaders need to consider when assisting patients to make difficult choices. Further, I discuss ways that advanced practice nurse leaders can be active and effective agents of change in regard to public policy in collaboration with governments and other stakeholders.

**Biotechnology: Promises and Pitfalls**

Biotechnological changes come in many forms, and most share common features with respect to ethics. These features include corporate involvement in development and diffusion of technology, a rapid proliferation of the technology, public pressure to make the biotechnology available, scientific progress with uncertainty, and inadequate attention to societal values.

Even though there may be little question that the capabilities and promises of biotechnology may be of benefit to society, there are concerns about the consequences of biotechnological innovation (O’Mathuna, 2007; Scheufele et al. 2007). For example, a worldwide pandemic and public health crisis brought about by SARS-CoV-2, instances of bovine spongiform encephalopathy (BSE, also known as mad cow disease), and avian flu have added to the fears about biotechnology and the crossover of viruses and other pathogens from animals and birds to humans (Health Canada, 2007, 2010, 2023; Kluger, 1997; Silva, 2010). These developments have resulted in more emphasis being placed on the need for exten-
sive societal discussion about the use of new technologies prior to their implementation.

Biotechnological development and decisions about how to use new technology have largely been under the control of “experts”—including researchers, governments, vested interest groups, and corporations—and have been highly politicized. Today, there is widespread agreement among a number of authors with diverse areas of expertise that societal input is required in the debate about the ethical issues that have surfaced in regard to biotechnology. Input from members of the public is required when making decisions about what type of research ought to be pursued, and also in the development of coherent public policy about the application of the innovations that emerge from the research. The call for public involvement regarding biotechnology policy and research comes from many sectors, and for many years has been a theme in health care system reviews, as well as in meetings to discuss biotechnology (Government of Canada, 2017; Nuffield Council on Bioethics). Although support exists for the idea that decisions about the research, use, and outcomes of biotechnology have major implications for society, input from members of the public has not always been sought. Further, in addition to the pivotal role members of the public could hold in determining the future direction for biotechnology, a substantial role is available for advanced practice nurse leaders and all health care providers (HCPs) to not only understand the ethical and societal concerns that surround the technology, but also to become involved in the ongoing debate about the manner in which to proceed with specific innovations (Canadian Nurses Association [CNA], 2006; National Academies of Sciences, Engineering, and Medicine; National Academy of Medicine; Committee on the Future of Nursing 2020–2030, 2021).

Involvement in decision making about biotechnology is paramount for the public, advanced practice nurse leaders, and all HCPs in order to ensure that important societal values and expert knowledge are infused throughout the decision-making process. To illustrate how this can and should occur, I turn to a discussion of the perplexing ethical and societal implications of biotechnology. Using xenotransplantation as an illustrative case, I first
provide an Ethics in Practice scenario to contextualize the discussion. I then review developments in the area, and the benefits and concerns linked to xenotransplantation, especially as these developments apply to pathogen transmission and informed consent. In addition, I elaborate on some of the challenges that arise in regard to corporate, research, and regulatory issues related to xenotransplantation. Next, I discuss public participation in biotechnology policy development, and provide an example of a comprehensive approach used when attempting to obtain citizen input into whether Canada should proceed with xenotransplantation. In conclusion, I discuss ways in which advanced practice nurse leaders can influence change in regard to biotechnological development and implementation.

**ETHICS IN PRACTICE 19-1**

**Xenotransplantation: An Illustration of the Benefits and Challenges of Biotechnology**

Judith is a nurse practitioner working within the transplant program in an urban quaternary care hospital, and with other members of the transplant team is responsible for the assessment, education, and support of potential kidney transplant recipients. One of Judith’s patients, Theo, is a 47-year-old married teacher and father of two adult children. Theo has been receiving hemodialysis for ten years and has been on the transplant waiting list for over five years. Judith has met with Theo and his family several times and has developed a trusting relationship with them.

Unfortunately, Theo has developed a number of complications from chronic renal failure, including severe peripheral neuropathy. He has exhausted all possibilities of receiving an organ from a living donor, as the family members who have been tested are not compatible donors, and no friends have come forward to offer him a kidney. In desperation, Theo put a message on a social media site asking people to respond if they could donate a kidney to him. Because of the number of negative responses he received, Theo removed the request after a few months. He has been unsuccessful in obtaining an organ from a non-living donor, partly because he has a high level of panel-reactive antibodies, and with the waiting list growing, and the number of organs available for transplantation from non-living donors decreasing, Theo realizes he could be waiting for some time to receive a kidney transplant. Theo’s only daughter is getting married in several months and he does not believe he will survive to attend her wedding and walk her down the aisle. He is quite despondent and is feeling absolutely
In the sections that follow, I review several of the ethical and societal issues related to xenotransplantation emanating from Ethics in Practice 19-1. Further, by addressing some of the questions posed above, I will identify ways in which Judith can demonstrate nursing leadership in the area of biotechnology.

In the sections that follow, I review several of the ethical and societal issues related to xenotransplantation emanating from Ethics in Practice 19-1. Further, by addressing some of the questions posed above, I will identify ways in which Judith can demonstrate nursing leadership in the area of biotechnology.
Ethical and Societal Implications in the Development of Xenotransplantation

Solid organ, tissue, and cell transplantation have progressed from being impossible to becoming commonplace, with millions of people worldwide benefiting from transplants over the years (Canadian Institutes for Health Information, 2023; Molzahn et al., Murray, 1992; Starzomski, 2002, 2021; United Network for Organ Sharing, 2023). With this success comes an increased demand for donor organs at a time of severe shortage, resulting in a growing number of individuals worldwide who die while waiting for suitable organs to become available.

Xenotransplantation has been proposed as one way to alleviate the shortage of organs, tissues, and cells available from non-living donors, and to reduce the need for living humans to donate organs—a surgical process that is not without risk (Schneider & Seebach, 2008, 2010; Soulillou, 2011). Significant ethical and societal implications of biotechnology are reflected in the debates that have surfaced around xenotransplant technology—debates that raise fundamental questions about social justice, informed consent, the relationships of people with one another as humans, human relationships with other species, the roles of researchers and corporations, and the role of expert and public stakeholders in making decisions about biotechnology development and implementation (Carrier et al. 2022; Fischer & Schnieke, 2022; Hughes, 2007; Johnson, 2022; Reardon, 2022; Shapiro, 2008).

The science of xenotransplantation has evolved over the past several decades, spurred on by major developments in genetics, transforming xenotransplantation into a treatment that has the potential to be clinically feasible. Most clinical developments in xenotransplantation have been in the area of cell transplantation, although there is growing emphasis on xenotransplant technology for solid organ transplantation. The need for an appropriate ethical framework is paramount if this clinical application is to be viable.

Although with xenotransplantation there is the potential to supply cells to treat such disorders as Parkinson’s disease and diabetes, and to supply tissues such as skin and bone for transplant purposes, my emphasis in this chapter is on the use of xenotrans-
plantation in the field of solid organ transplantation. While xenotransplantation can occur between animal species, I will centre my review on transplantation of solid organs from animals to humans.

A major problem in the clinical application of xenotransplantation has been finding a suitable source animal from which to retrieve organs that will not be rejected by the human recipient (Carrier et al., 2022; Fischer & Schnieke, 2022). In the early days of xenotransplantation, the source animals were generally non-human primates. An example of such a case was that of newborn Baby Fae, one of the first humans to receive a xenograft (an organ from a donor of a different species than the recipient). The case received much media attention in 1984 when Baby Fae received a heart transplant from a baboon to treat a condition often fatal in the first days of life called hypoplastic left heart syndrome—a condition in which the left atrium and ventricle are seriously underdeveloped. She died a few weeks post-transplant amid considerable controversy about the cause of her death, since her heart did not show evidence of cellular rejection (McCormick, 1985; National Institutes of Health, 1985; Veatch, 2000). In the midst of the analysis and disputes after her death, xenotransplantation trials in humans were stalled because of the concerns related to possible organ rejection.

Non-human primates have been removed from consideration as source animals for xenotransplantation, partly because of the high risk of unknown infections being transmitted from them to humans, as demonstrated by the human immunodeficiency virus (HIV) pandemic (Allan, 1996; Cozzi et al., 2009). Further, major animal rights concerns exist regarding the use of non-human primates for research because of the close genetic link of these animals to humans (Johnson, 2022; Rollin, 2003, 2020; Singer, 1992). Also, their long gestation period raises concern that insufficient numbers of animals could be bred to meet the need for organs.

Currently, the source animals of choice for xenotransplantation are transgenic pigs. Source animals, such as pigs, can be altered by genetic engineering, including genetic technologies like clustered regularly interspaced short palindromic repeats (CRISPR), to minimize rejection, thus optimizing organ function and providing potential advantages to the recipients (Carrier et al., 2022; Fischer et al., 2016; Fischer & Schnieke, 2022). While some risks are reduced
with the use of pigs as source animals because of their greater phylogenetic distance from humans, and the ability to breed them quickly in pathogen-free, closed environments, the risks associated with unknown infectious agents cannot be quantitatively assessed. Because of the difficulties, few solid organ xenotransplants have been conducted worldwide. Most of the transplants done to date have been for short-term bridging purposes—that is, while critically ill human recipients waited for human organs to become available.

This situation is changing, however, as scientific developments in the area of xenotransplantation are accelerating. It is now possible to clone pigs, and scientists are altering genetic systems in order to reproduce litters of piglets with organs that the human immune system will not reject. Companies have cloned pigs and “knocked out” the specific gene that has been implicated in transplant rejection, thereby moving the possibility of successful xenotransplantation closer to reality. Recently, a pig heart was transplanted into a human in the United States (US) through a “one-off” approval by the United States Food and Drug Administration (FDA) on grounds of compassionate use for a patient in a critical situation where no other options were available to the patient (Johnson, 2022; Sade & Mukherjee, 2022). In addition, in the US, Montgomery et al. (2022) described the results of two cases of pig-to-human kidney transplants in neurologically dead recipients. As a result of the rapidly increasing scientific development in this area, many countries in the world have been working to create appropriate regulatory frameworks for xenotransplant human clinical trials and the therapeutic application of the technology, a topic I will take up later in this chapter.

**Natural Law**

Xenotransplantation, similar to other types of biotechnological innovation, is the focus of much controversy and debate, raising complex ethical, social, legal, and economic issues (Caplan & Parent, 2022). The issues raised by xenotransplantation reflect the diversity of values, beliefs, and attitudes held by members of society about vital questions regarding who we are as humans, and our role in the natural ecological order of our planet (Rollin, 2020). Such questions
are also important when discussing other forms of biotechnology within areas such as AI, genetics, human reproduction, nanotechnology, regenerative medicine, and robotics.

Societal beliefs, attitudes, and values about the nature of xenotransplantation are diverse. Some opponents of xenotransplantation suggest that the technology raises a problem of natural law because the intermixing of biological material from different species violates fundamental morality, impacting directly on who we are as humans (Canadian Public Health Association [CPHA], 2001; Veatch, 2000). Some who support xenotransplantation propose that although the transplantation of organs from one species to another is cause for concern at first, it does not involve any more of a violation of natural law than does transplantation of an organ from one person to another, as long as the animal is treated with respect (CPHA; Veatch).

This diversity of societal opinion about the nature of xenotransplantation was clearly articulated by participants in a study where focus groups were held with 34 consumer and HCP groups to determine their attitudes and beliefs about a number of ethical issues related to organ transplantation, including xenotransplantation (Starzomski, 1997). In the following quotes, taken from transcripts of the focus group discussions, participants expressed their thoughts about xenotransplantation. For instance, one critical care nurse expressed her concern about xenotransplantation when she said,

I’m a Christian, and I believe that death all along is natural; we are not immortal, and I see it as the final course of life, isn’t it? And that’s why, when you mentioned the pigs, I go no way! Because that is going to the mad scientist stage, and it’s just beyond [imagination].

Providing a different view, an advanced practice nurse said, in her interview,

I would support it [xenotransplantation] as long as we are using, in real valued things, a lower-order animal like a pig (and I think there is still enough research done to know they already are lower-order animals) versus finding out later that they are actually smarter than we are, like the
whales kind of thing. So, if there were some scientific assurances that that is the case then somehow I could bring myself to accept that. …

It sounds like a good idea, we eat them [animals] anyway, so we’re not that sentimental about them. I wouldn’t like to see them terribly exploited, but we exploit all over the place.

These opinions, generated by reflection on personal values, underscore several of the germane concerns related to xenotransplantation. What follows is a review of some of the benefits and challenges related to xenotransplantation, including further exploration of many of the issues that have been raised in the discussion about biotechnology.

**Benefits and Challenges of Xenotransplantation**

Although xenotransplantation has the potential to benefit many people, a number of societal and ethical concerns must be addressed if this technology is to move forward in a manner that optimizes its potential to benefit people while at the same time minimizing risk. I review the major benefits of xenotransplantation and discuss some of the potential problems that work against these benefits. Given the limited scope of this chapter, I will not address one of the concerns raised by xenotransplantation—that is, the rights of the animals who will be the donors if xenotransplantation becomes a reality (CPHA, 2001; Haddow et al., 2010; Singer, 1992). For readers who would like to have more information about this topic, I include references that provide further background with respect to the animal rights challenges related to xenotransplantation.7

Many potential benefits have been identified if xenotransplantation were to become a therapeutic treatment for end-stage organ failure. These include the following:

- The potential to eliminate the shortage of organs, tissues, and cells, as facilities would be established to produce pigs to serve as sources that would be available when required.
• In some jurisdictions where human organ donation has not been accepted because of ethical or ethnocultural concerns, xenotransplantation might provide an acceptable alternative.

• With ready access to organs, recipient selection criteria could be broadened, and the ethical dilemmas surrounding transplant allocation would diminish, as everyone who needed an organ could theoretically receive one.

• Xenotransplants could be done in an early, controlled fashion before the complications of diseases affected patients.

• Xenotransplants could offer advantages similar to those associated with the use of human living donor organs. For example, the transplant surgery could be pre-scheduled; pre-treatment of recipients would be possible; the quality of the organs would be known; the organs would be out of the body for a limited amount of time, thereby preventing rejection; and the effects of neurological death on organ quality could be avoided.

• Finally, xenografts might not be susceptible to the human autoimmune diseases or viral infections that caused organ failure initially in some patients, and which often limit the survival of organ transplants from human donors (Council of Europe, 2003; Gunzburg & Salmons, 2000; Nuffield Council on Bioethics, 1996; Sykes et al., 2003).

In this review of the possible benefits of xenotransplantation, I show that biotechnology has the potential to provide therapeutic advantages in health care delivery. Benefits similar to the ones described above exist for other biotechnologies. For instance, by using successful gene therapy and cloning technology, HCPs could make treatments available that are tailored to an individual’s genetic profile, thus preventing further disease and disability.

Although xenotransplantation offers benefits, a number of scientific and ethical barriers exist that must be addressed to ensure that advances in biotechnology are developed in a manner that optimizes their potential to benefit society. At the same time, it is important to consider how to minimize risk for individuals and communities.


**Risk of Pathogen Transmission**

One of the significant societal and ethical concerns involved in xenotransplantation is the worry about the risk of transmission of animal pathogens to humans and the subsequent consequences for society. As with all mammals, pigs have viruses that are active, latent, or represented only by a partial genetic sequence embedded in the pig genome. It is difficult to assign exact numbers to the risk, but many experts agree that it is possible that pig endogenous retroviruses (PERVs) could be transmitted to human xenograft recipients (Carrier et al., 2022; Fischer & Schnieke, 2022).

The possibility has arisen that, under specific conditions, PERVs can be carried in tissue that is transplanted, and can infect human cells. Because PERVs could be transmitted to human xenograft recipients, it is further possible that such infections could be passed from recipients to other humans, and to members of society at large. Some authors have indicated that these fears are not unfounded by suggesting that technology in antibody screening for potential xenozoonoses is fraught with problems and needs further study. Although investigators disagree about the magnitude of the risk, few dismiss it, and many agree that it is sufficient to merit serious concern (Caplan & Parent, 2022; Carrier et al., 2022; Fischer & Schnieke, 2022).

Further complicating the issue of disease transmission is the reality that if researchers were aware of a particular virus or pathogen, they might be able to develop a test to determine if the pathogen was present. However, if it were a pathogen that had not yet been recognized, it would be impossible to determine if an animal were pathogen-free. This is a very serious concern, as precedents exist for the survival, replication, and spread of animal viruses to humans with subsequent human-to-human transmission. For example, some scientists believe that HIV might have originated in monkeys before spreading to humans (Allan, 1996). In addition, some epidemiologists believe that the H1N1 virus (Spanish flu) that killed close to 50 million people worldwide in the early part of the 20th century might have been triggered by genes of avian origin (Jordan et al., 2019). It is also thought that the H5N1 influenza virus that struck Hong Kong in 1997, killing 18 people, was
spread from ducks to chickens to humans. Experts indicate that if
the outbreak had not been stopped in time, it would have caused a
pandemic (Evanson, 2000).

In 2002 and 2003, severe acute respiratory syndrome (SARS),
caused by a coronavirus called SARS-associated coronavirus (SARS-
CoV), and thought to have moved from bats to humans, quickly
spread to many countries, infecting over 8,000 people and killing
774 (Centers for Disease Control and Prevention, 2017). Other
situations linked to the jump of pathogens from animals to humans
include the Ebola and Lassa fever outbreaks in Africa (Nnaji et al.,
2021). In the case of SARS-CoV-2 (COVID-19), there is speculation
that the virus might have emerged from animals in a wet market in
China, although others believe that it might have emerged from a
laboratory setting (Khullar, 2023).

Many gaps exist in our knowledge of the potential risks of dis-
ease transmission if xenotransplantation were to become a reality.
Risks cannot be eliminated based on current evidence, and the
uncertainty about the safety of xenotransplantation continues to be
a significant obstacle to its implementation. Cloning and genetic
modification techniques to address disease transmission are still in
process. Further scientific information may close the gap some-
what, but it may never be possible to say with absolute certainty that
the risk is absent. Xenotransplantation falls into the category of
experimental treatment where, although the risk is perhaps low,
and the benefits to humans substantial, the consequences for
humanity could be catastrophic (Caplan & Parent, 2022). As one
member of the public in the 1997 study by Starzomski said,

You know at this point, I think it [xenotransplantation] is a
good idea, but where will it lead? I’m not sure, and I don’t
think any of us know where DNA manipulation is going to
lead. It could be really scary stuff, and we need the answers
to the questions, I suppose, to think about it at this point. I
worry about the transmission of disease. What will happen
to our world if we get another bug like HIV?
Concerns About Informed Consent

The tension between individual and societal rights is part of the difficult ethical debate about xenotransplantation. While participants often accept risks arising from experimental treatment, believing them to be balanced by the potential benefits, one important distinction between xenotransplantation and other treatments is that xenotransplantation may put individuals other than the recipient at risk of contracting disease. The concept of informed consent for individual patients is a central principle in Western health care delivery. When faced with health care decisions, the patient is informed of the various alternatives for treatment and the relative risks and benefits of each option. Given that scientists in the area of xenotransplantation cannot answer all the questions about possible risks, a potential patient would be put in a very difficult situation if they were considering being a participant in a clinical trial. In addition to consenting to the procedure, participants would have to consent to lifelong surveillance, including medical monitoring and follow-up. They would also have to consent to the archiving of their biological specimens when appropriate. Further, they would need to inform intimate contacts of potential risk, thus causing many privacy concerns for potential recipients (American Medical Association, 2017; FDA, 2016a, 2016b).

As evident in Ethics in Practice 19-1, the risk is not restricted to the individual who is receiving the xenotransplant, but is also of concern to close contacts, family members, and indeed the community at large. Xenotransplantation raises the problematic challenge of applying the principle of informed consent to an entire community, since the community as a whole would be potentially exposed to the risk (Hughes, 2007). The risk posed to the community by possible xenozoonosis after xenotransplantation requires that some form of “community consent” is necessary before solid organ animal-to-human xenotransplantation takes place. As the relevant community is global, and there are no existing agencies with the appropriate credentials sufficient to establish this consent, this presents obstacles to the implementation of xenotransplantation (World Health Organization, 2003).
In Ethics in Practice 19-1, Judith, the advanced practice nurse, will have to ensure that Theo has information about the risks of xenotransplantation and, as part of her responsibility, ensure that information is conveyed to Theo’s family as well. To gain support in this work, Judith could access information about xenotransplantation, such as national standards and guidelines, which she could explain and interpret for Theo and his family. Even though Theo is not currently enrolled in a clinical trial, Judith might find it useful to review information available about the role of the nurse in research (as described in Chapter 2) to help determine what could and should be conveyed to Theo and his family.

But what of the larger community? What is Judith’s responsibility to it? Viruses and other infectious agents do not respect national borders. The 2003 cases of SARS and BSE have made that evident and, more recently, the COVID-19 pandemic has made it clear that viruses know no boundaries. Along with other HCPs and health care researchers, advanced practice nurse leaders have a responsibility to ensure that information about issues such as xenotransplantation, genetics, and regenerative medicine that are within the realm of their practice are discussed in the community. Further, it is essential that informed representatives of the public are given an opportunity to participate actively and meaningfully in the decisions about whether, and under what conditions, society is exposed to the risks associated with these and other biotechnological developments. If it is unethical to impose a health care risk on a patient, it is also unethical to expose the public to a risk without first considering societal opinion. Strategies for advanced practice nurse leaders to become involved in the community at large in order to facilitate discussion about biotechnological advances will be discussed in more detail later in this chapter.

**Corporate and Research Influences on Xenotransplantation**

Xenotransplantation is a big business, and it poses challenging problems from the perspective of business and corporate ethics, as well as research ethics. The economic implications are considerable, and many pressures are brought to bear by stakeholders for whom
these considerations are at the forefront. For example, the market for organ and tissue transplants in the US is thought to be worth billions of dollars, thus providing a huge potential market for biotechnology companies. Many companies have invested heavily in the area of xenotransplantation and are eager to see their investments be profitable (Loring et al., 2022).

When considering the diffusion of new biotechnologies, it is important to ask questions about who is likely to benefit from the various types of biotechnology, and who is likely to suffer from them (Sherwin, 2000). It remains to be seen whether or not xenotransplantation and other technologies, such as gene therapies, will be accessible to the poor and disadvantaged. In the past, pharmaceutical and medical technologies have been readily available in the Western world but not accessible to over half of the world’s population, who do not have access to even basic health care (MacNeill & Jacobs, 2019). Furthermore, issues regarding conflict of interest and research ethics have had an impact on how companies choose to study new technologies and make them available globally (Neufeld et al., 2001).

Because many Western governments have been unwilling to allow xenotransplant clinical trials, corporations and some investigators moved to other countries to pursue research and human clinical trials (BBC News, 2002; Sykes & Cozzi, 2006). Clinical trials in some countries, conducted under weak safety rules, opened the door for “international xenotourism,” where desperate patients have bypassed tight regulations for treatment in some developed countries. Failure to implement international regulations, or loose interpretation of standards, have the potential to adversely affect already disadvantaged groups and populations, and possibly give rise to worldwide risks.

Although some countries do not have the appropriate regulatory authorities to develop and maintain suitable guidelines to safeguard patients and their contacts, pressure from international bodies has sometimes influenced practice. For example, a number of years ago, clinical trials in children with Type 1 diabetes were conducted in Mexico. People from other countries came to Mexico for islet cell xenotransplants, but the trials were shut down
when it was found that international ethical standards were not upheld (Cook et al., 2011).

It can be argued that in developing countries, biotechnology research is inappropriate when people are living without the basics of preventive care, maternal and child health services, and other fundamental health care needs (Veatch, 2000). Xenotransplantation raises significant questions of international justice since there is the potential to place the lives of citizens of poor nations at risk to benefit the citizens of wealthy nations (Sparrow, 2009).10

Another challenging problem that falls within the corporate and research realm is the lack of access to data from international clinical trials of xenotransplantation. Usually, such data, and any adverse reactions resulting from treatment, is confidential, and may only be made public at the discretion of the sponsor, something that generally only happens if positive outcomes are observed. Therefore, corporate and research issues and concerns must be part of the public debate about biotechnology. There is a need for members of the public and HCPs to work together with corporations and investigators to ensure that they are able to meet their ethical and social responsibilities. Shareholders, and society as a whole, must hold corporations and researchers accountable in future work related to xenotransplantation, as well as innovations coming from research in areas of biotechnology.

**Regulatory Concerns**

There are a variety of approaches used to regulate xenotransplantation research in different jurisdictions around the world. In Canada, xenotransplantation studies are currently being carried out using laboratory animals only. These pre-clinical or experimental trials do not involve human patients and are not regulated by Health Canada. Xenotransplants for humans are considered therapeutic products and can only be used in clinical trials if authorized by Health Canada (Health Canada, 2010); to date, no such authorization for human xenotransplant trials has been given. For Health Canada, one of the principles guiding the identification and evaluation of risks related to xenotransplantation has been the Government of Canada's proposed precautionary approach or
principle. This is an approach used to manage threats of serious or irreversible harm when there is scientific uncertainty (Fovargue & Ost, 2010; Government of Canada, 2001). In the US, xenotransplant human clinical trials are approved and are tightly controlled. All experiments using animal tissues must be cleared through the FDA (FDA, 2016a, 2016b).

As scientific knowledge about xenotransplantation increases, there is still no consistency across the world about the status of xenotransplantation, or how regulatory frameworks are developed and implemented. Countries worldwide have been implementing a wide range of decisions about xenotransplantation research and clinical trials, from outright bans and moratoriums to more relaxed safety rules (Cheng, 2015; Health Canada, 2010; Tallacchini, 2008). Some authors have suggested that what is needed is a coordinated international effort by the World Health Organization aimed at harmonizing xenotransplantation protocols in accordance with the best available scientific data and with the highest ethical and regulatory standards, to ensure that clinical xenotransplantation trials will be conducted with minimal risk to society.

The Ethics Committee of the International Xenotransplant Association (Sykes et al., 2003) suggested that trials on humans should only be performed with oversight from a governmental regulatory agency with guidelines similar to those developed in Western countries. The committee proposed that the trials should include information about the source animals, as well as monitoring procedures for xenotransplant research subjects and, where deemed appropriate, their close contacts. In addition, the group suggested the development of a national repository for holding specimens from human subjects in countries in which clinical trials are conducted and, if a repository was not possible, then specimens should be properly obtained, tracked, analyzed, and stored. The committee went on to recommend that in the absence of such oversight and monitoring, clinical xenotransplantation should not occur. The committee proposed that the International Xenotransplant Association take leadership in facilitating the development of universally accepted procedures, standards, and guidelines about xenotransplantation since many countries around the world were beginning xenotransplant programs. Like others involved in xeno-
transplantation, the committee raised the concern that without such co-operation, efforts of countries to minimize the potential risks would be jeopardized, because of concerns about xenotourism; that is, the potential travel of individuals who received a xenotransplant in a country without regulatory guidelines (or close contacts of those individuals).

Although the issues discussed here are focused on xenotransplantation, they are also applicable to other biotechnologies, where similar regulations are required and are being discussed in many countries. Clearly, decisions about biotechnology require broad societal discussion and debate.

**Public Participation in Decisions About Xenotransplantation**

Members of the public are often overlooked as participants in the discussions about biotechnology (Abelson et al., 2010; Lenaghan, 1999). In order to ensure that the required values and perspectives are represented, multiple voices are needed in the debate about biotechnology, with a prominent position for members of the public. The idea of public and HCP involvement in decision making is supported, but how can this become a reality? Many people have been proponents of the public becoming more involved in decision making about technological diffusion into society and health care (Ivinson & Bach, 2002; Kögel & Marckmann, 2020). Decades ago, Winner (1993) proposed broad involvement in decision making about technology, and pointed out that there was no moral community or public space in which technological issues were topics for deliberation and common action.

Brunger and Cox (2000), in their discussion about genetics and ethics, suggested strategies for widening the space of public debate about technology, including providing the public with information about the production, distribution, and application of knowledge; legitimizing lay knowledge; attending to a multiplicity of voices; welcoming dissent as a sign that all voices are being heard; allowing the debate to be transparent in public; and promoting the accountability of government, industry, and science to the public. Other authors have proposed several conditions that must be met
for meaningful public participation to occur in health care decision making, including assuring that consumers have adequate information; that there are a majority of consumers in the decision-making group; that there is a strong mandate from the community with formal and informal access to constituents; and that people selected to represent communities are confident enough not be intimidated or dominated by the so-called experts within the group (Abelson et al., 2010; Montesanti et al., 2017; Starzomski, 2002). What follows is a description of a public consultation process in which these strategies were evident in the discussion about whether Canada should proceed with xenotransplantation and, if so, under what conditions. This example stands as one of the most comprehensive processes ever undertaken in Canada to involve the public in decision making about the implementation of biotechnological developments.

In 2000, Health Canada provided funding to the CPHA to strike a Public Advisory Group (PAG) to conduct an arm’s length public consultation to hear the views and concerns of Canadians about xenotransplantation. The PAG was given the task of reporting back to the federal minister of health with recommendations about whether Canada should proceed with xenotransplantation. Members of the PAG represented a diversity of perspectives, regions, and interests. The process they designed included several options for Canadians to voice their opinions, including a telephone survey of 1,519 randomly selected adults; opportunities to submit letters, faxes, and emails to the CPHA office and website; a “have your say” questionnaire (which was located on the CPHA website and also mailed to 3,700 organizations); and regional citizen forums (sometimes also called citizen juries) of between 15 and 23 demographically representative citizens. These citizen forums were held in six major cities across Canada. The forums were moderated by a bilingual professional facilitator who travelled to each city, and included opportunities for panellists to have discussions with experts and review resource material in the area of xenotransplantation. In addition, during each forum, prior to the private panellists’ meeting, time was allocated for members of the general public to participate in the discussion (CPHA, 2001; Einseidel & Ross, 2002).
Before the two-and-a-half-day forums were held, the members of the citizen juries were asked to complete a questionnaire to determine their attitudes and beliefs about xenotransplantation. Many participants held a positive view, but after discussing the risks and concerns during the forums, the majority changed their thinking, concluding that Canada should not proceed with xenotransplantation at that time: 34% said no; 19% said no with qualifications; and 46% said yes with qualifications. It appeared from these results that the more Canadians learned about xenotransplantation, the more concerned they became. Although not absolutely opposed to xenotransplantation, the forum participants favoured a precautionary approach, expressing concerns about uncertain health risks, an insufficient level of scientific knowledge in the area of xenotransplantation, and inadequate regulations (CPHA, 2001; Wharry, 2002).

In contrast to the citizen jury experience, in the telephone survey of 1,519 Canadian adults, 70% were not very, or not at all, knowledgeable about xenotransplantation and yet, of this number, 65% supported clinical trials. These findings must be interpreted cautiously, as they illustrate some of the problems that occur when public opinion polls (where participants have little information about the issues) are used to solicit opinions about complex areas such as xenotransplantation. The final report of the PAG included the results of the complete public consultation process. It was delivered to the minister of health and subsequently released publicly in 2002 (CPHA, 2001). In the report, the CPHA did not close the door on xenotransplantation, but rather called for more research into potential risks, suggesting that those who wish to proceed with xenotransplantation need to determine the level of risk and demonstrate how the benefits of the procedure would outweigh those risks. In addition, among the recommendations, the CPHA suggested that non-human pre-clinical research would be acceptable, as this could provide more information about the viability of xenotransplantation. There was also a call for more stringent and transparent legislation and regulation covering all aspects of xenotransplant clinical trials. Further, it was recommended that Health Canada consider alternatives, such as disease prevention, the development of mechanical substitutes, and pursuit of stem cell research to
expand the human donor pool. Finally, the authors of the report suggested that efforts should continue to further the knowledge and public discussion of xenotransplantation, and that the citizen forum model be considered for future consultations on complex and poorly understood health-related policy issues.

The consultation process described here for xenotransplantation is a model for other areas where innovations in biotechnology are occurring. Regardless of the particular approach taken, if public consultation of this sort is to be effective, it is crucial that participants be well informed. All sides of the issue must be presented without attempts to steer the dialogue, allowing the public participants to arrive at their own conclusions. However, even with possible flaws (Wright, 2002), the CP SHA process to solicit public opinion about xenotransplantation stands as one of the only comprehensive experiments in Canada to engage the public in discussion about decisions regarding the diffusion of a new biotechnology into the health care system.

The practice of public consultation in biotechnology does not mean, however, that a few public representatives set policy. Such groups are not representative of the whole population and are not selected to represent the entire community. In the example described above, the PAG report was presented to the minister of health to inform the decisions that must be made by policymakers and the political representatives to whom citizens delegate such authority. The CP SHA experience has provided valuable information about including the values of the public in decision making and engaging citizens in the debate about biotechnology development in Canada.

Health Canada notes on its website that xenotransplantation is currently not prohibited in Canada. However, as the live cells, tissues, and organs from animal sources are considered to be therapeutic products, xenotransplantations are subject to the requirements of the Food and Drugs Act, the Food and Drug Regulations or the Medical Devices Regulations (Health Canada, 2010). To conduct a human clinical trial, a sponsoring company or research institute would have to apply to Health Canada for approval before proceeding. At the time of writing this chapter, no human
clinical trial involving xenotransplantation has yet been approved by Health Canada.

The public must be involved in all facets of societal development. In particular, in creating policy about biotechnology, it is clear that public values are essential in making ethical choices that will benefit the community. Good health care decisions are not possible until the public has the opportunity to help choose the goals, priorities, and means that guide policy development.

There is a major role for nurses in ensuring that diverse voices are heard in discussions about biotechnology (Care et al., 2014). In the Ethics in Practice 19-2 scenario, an advanced practice nurse leader is presented with a challenge when promoting appropriate stakeholder engagement in making decisions about new biotechnological developments in cancer care.

In what follows, I discuss the implications for advanced practice nurse leaders in helping to open the moral space required for discussion about the ethical and societal implications of biotechnology. The debate becomes all the more vital and complex with the introduction of ever-more-powerful biotechnologies that may offer potential benefits to individuals, but may be counterbalanced by potential risks to individuals or to large populations.

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**ETHICS IN PRACTICE 19-2**

**A Community Biotechnology Challenge**

Frank is a clinical nurse specialist working in a cancer centre in a large city and has been asked to join a committee examining cancer treatments that combine targeted and immune therapies to kill treatment-resistant cancer cells. At the first meeting, Frank is worried that ethical questions have not been raised about the overall effectiveness of treatments, given their side effects and their impact on patients’ quality of life. Furthermore, he is concerned that the cancer patient community has not been involved in discussions about if and how these treatments might be used. When Frank’s concerns are raised in the committee, a number of the committee members suggest that these worries are unfounded, as researchers have demonstrated that all the therapies are useful.
In a rapidly changing world, we are inundated with information about the “good, the bad, and the ugly” of biotechnological innovations, as we seek to interpret the vast amount of data that we are exposed to on a daily basis. Kingwell (2002) suggested that as conscientious citizens, we struggle to stay on top of what is happening in our technologically dominated complex world, and advised that we need to prepare ourselves for a “bumpy ride” as we try to determine where we are headed. Further, Saul (2001) pointed out that there are severe limitations to what we can understand in the face of constant technological change. He reminded us that “[i]n fact, with the explosion of technology over the last quarter-century, the percentage of what we understand versus what we know has probably slipped back to where it was a century ago” (p. 30).

As nurses, how do we sort through the information that is available, organize ourselves for the “bumpy ride,” and ensure that we are prepared to deal with the societal and ethical implications of biotechnology? It is a difficult undertaking, as the line between science and science fiction has become blurred, a plethora of information is available, and many conflicting points of view exist. We only have to review recent newspaper and magazine headlines to emerge with a sense of the complexity of the information
provided for our perusal and the variety of perspectives and opinions that are presented to the public.

In this book, and elsewhere, there has been a call to expand social, environmental, and political thinking in nursing, and a call for a focus on the common good, a term used to describe the well-being of the community at large based on shared goals and common purposes (Starzomski & Rodney, 1997). Nurses need to be involved in understanding and facilitating broad societal discussion of issues related to transplantation and biotechnology as these technologies can influence profound change in the human capacity to control diseases and human reproduction (Care et al., 2014; CNA, 2006, 2017; National Academies of Sciences, Engineering, and Medicine et al., 2021; Starzomski, 2021). One of the most significant challenges that advanced practice nurse leaders will face in the future will be to find the balance between maximizing the benefits of using biotechnology in health care, while at the same time ensuring a humanistic, relational focus for care.

The Canadian Nurses Association has made claims about the importance of the involvement of nurses and the public in making policy decisions about biotechnology. In several position statements, documents, briefs, as well as in their 2017 Code of Ethics for Registered Nurses, the CNA expresses support for including nurses in discussions about technology at all levels of the health care system. They suggest that nurses must be involved in all aspects of technology use, including identifying the need for such use, developing and implementing technology, and evaluating the impact on client care. CNA policy statements, such as those related to technology, primary care, and leadership, all include some reference to supporting a nursing role in discussions about technology development and implementation (CNA, 1992, 1995, 2002, 2006). Further, the CNA has shown national leadership in the area of biotechnology by promoting the involvement of expert nurses on committees and councils where decisions about biotechnology are made.11

Understanding the scope of biotechnology can be overwhelming. It is neither practical nor possible for every nurse to keep abreast of all the ethical and societal developments; nor is it possible to speak out on every issue, as the issues are numerous and priorities vary. However, advanced practice nurse leaders can act as
expert navigators of biotechnology and become information brokers for their patients and colleagues, while ensuring that the core values of nursing are maintained. Further, there is a need for advanced practice nurse leaders to examine the impact of biotechnological changes on nursing recruitment, nursing work design, and the nursing workforce. An understanding of nursing ethics can prepare advanced practice nurse leaders to deal with the challenges confronting them when addressing the use of biotechnology in health care. A background in nursing ethics can also enable advanced practice nurse leaders to critically examine the issues and influence change in the use of biotechnology when needed. It is essential that in this work, advanced practice nurse leaders engage in discussions with diverse HCPs and members of the public to ensure that the best decisions are being made.

Returning to Ethics in Practice 19-1, Judith faced a number of ethical challenges. In reflecting further on the ideas presented so far in this chapter, the micro-, meso-, and macro-level strategies that follow would be useful for Judith to consider as she develops her plan about how to support Theo and his family.

Micro-level strategies include

- Becoming educated about biotechnological developments and the associated societal and ethical implications.
- Ensuring that patients and families are informed about options, risks, and benefits when considering therapeutic biotechnological interventions.
- Helping to educate other nurses, HCPs, and members of the public about biotechnology.
- Ensuring that ethical and societal issues about biotechnological developments are part of educational curricula, conferences, and symposia for nurses and other HCPs.
- Engaging in advocacy to help patients and families have opportunities to express their views regarding biotechnological interventions.
Meso-level strategies include

- Participating in both clinical and research ethics committees where issues about biotechnology are being discussed.
- Conducting research examining the ethical and societal implications of biotechnology.
- Ensuring that ethical and societal issues about biotechnological developments are part of hospital, community, regional board, and health authority discussions.

Macro-level strategies include

- Participating in national committees, debates, and forums about health care and biotechnology.
- Working with provincial professional associations and organizations to ensure that there is public dialogue about biotechnological concerns.
- Using methods such as citizens’ juries, consensus conferences, town hall meetings, and social media to engage the public and HCPs in debates about biotechnological issues.
- Participating with professional associations to ensure that nurses are represented in the federal government and provincial/territorial legislatures where laws are being made that govern biotechnology.

There is no doubt that, in the future, decisions about biotechnology will continue to demand the involvement of advanced practice nurses, all HCPs, and the public. These decisions will be complex and difficult, and no one societal group or set of voices will be adequate to make the choices that are needed. Although, as a society, we may not always have the answers to questions related to choices about biotechnology, a collaborative effort will provide the best method to ensure that wise choices are made for future biotechnological developments and their implementation.

**Future Directions: The Tip of the Iceberg**

The use of biotechnology raises major issues—issues about ethics, choice, trust, democracy, and globalization. Innovations in biotech-
nology are encumbered with intended and unintended social, political, and economic values. I have argued throughout this chapter that policies surrounding xenotransplantation, and other emerging biotechnological interventions, must be developed by those who consider the importance of balancing opportunity and risk. Further, I have advocated for an expansion in the debate about biotechnology that includes members of the public, advanced practice nurse leaders, all nurses, and other HCPs in discussions about the societal and ethical issues facing us in the realm of biotechnology.

Public involvement in decisions about biotechnology is complex. While there is no consensus about how to include the public in meaningful ways in the development of healthy public policy, in this chapter I have presented several methods that I believe move us in the right direction. Clearly, we need to be sensitive to the contexts where public participation is being sought, in order to ensure that citizens are able to avail themselves of opportunities to be informed and involved (Abelson et al., 2010; Maxwell et al., 2003; Mitton et al., 2009). This is an area where “one size does not fit all” (Martin et al., 2002).

Although the future of collaborative dialogue and debate on issues of biotechnology is by no means assured, there are promising signs of progress. As discussed throughout this chapter, researchers, as well as governmental and non-governmental organizations, are focusing more attention on biotechnological issues. The xenotransplantation public consultation process in Canada was one example of a move in that direction. It is important to seek meaningful societal participation regarding the issues facing us in biotechnology, in order to make the best possible choices about future technological opportunities that are coming our way.

By its very nature, science alone will not give us answers with absolute certainty and can only tell us about the likelihood of the benefits and dangers posed by biotechnology. As citizens, we will need to continue to review the science and to make decisions based on our value systems, as the current ethical challenges in biotechnology are really just “the tips of icebergs.” The future possibilities in biotechnology are beyond our imaginations, and for many may seem like science fiction.12 Research in areas such as AI, genetics, human reproduction, nanotechnology, robotics, regenerative medi-
cine, and xenotransplantation may offer opportunities to address some of our health care concerns; but, in the future, the success of these approaches will depend not only on scientific development, but also careful consideration of the related ethical and societal issues.

Before us is a period of remarkable biotechnological innovation. We have added more innovations that influence life and death to our armamentarium. Will we use biotechnology to preserve our humanity and improve our quality of life, as exemplified in the optimistic future portrayed in *Star Trek*? Or, will we choose a more pessimistic future such as that portrayed in Aldous Huxley’s *Brave New World* (1932), where humans have really become the tools of their tools? The manner in which we develop and use biotechnology today is a harbinger of what we can become as a society tomorrow. We must choose wisely, keeping in mind that the wisdom we need for tomorrow comes from understanding the present and learning from the past.

**QUESTIONS FOR REFLECTION**

1. *Think about your work setting and your role within your family and community. How can you facilitate discussion about the biotechnological innovations that affect you in those spheres of your life?*

2. *How can advanced practice nurse leaders hold decision makers accountable about whose best interests are being served by various biotechnologies?*

3. *What social justice issues arise in everyday nursing practice from decisions about biotechnology?*

4. *How can public input be obtained about the use of biotechnological developments in areas such as AI, genetics, human reproduction, nanotechnology, regenerative medicine, robotics and xenotransplantation?*

Biotechnology is the application of science and engineering to the use of living organisms or their constituent parts with the intent to modify human health and the human environment (Dahms, 2004).

Please see Chapter 14 (Disabilities and Health Care) and Chapter 17 (Genetics and Identity) in this book for more details.

Nanobiotechnology is a branch of science which includes structures or functional materials at the nanoscale that are produced by employing both physical and chemical methods (Hobson, 2016). Regenerative medicine may be defined as the process of replacing or “regenerating” human cells, tissues or organs to restore or establish normal function (Association for the Advancement of Blood and Technologies, 2023).

Please see Chapter 17 (Genetics and Identity) and Chapter 18 (Digital Health Technologies) for many examples of how new technologies are being used in health care.

“Transgenic refers to an organism or cell whose genome has been altered by the introduction of one or more foreign DNA sequences from another species by artificial means” (National Human Genome Research Institute, 2023, para. 1).

Please see Prater (2021), Weintraub (2022), and Kwisda et al. (2020).

A zoonosis is an infectious disease that has jumped from a non-human animal to humans (Centers for Disease Control and Prevention (2021).

For more information, refer to Chapter 9 (Promoting Health Equity) and Chapter 20 (Global Health Ethics) in this book.

Although further discussion of these global issues is beyond the scope of this chapter, please see Chapter 1 (Nursing Ethics) for a more comprehensive discussion of the principle of social justice and Chapter 20 for an in-depth discussion of ethics and global health.

The author of this chapter was nominated by the CNA to sit on Health Canada's Expert Advisory Committee on Xenograft Regulation and was a member of that group for several years.

For enlightening perspectives on biotechnological development, see Klara and the Sun, a novel by Kazuo Ishiguro (2021) and Margaret Atwood’s (2003) book Oryx and Crake—a novel about xenotransplantation.
References


Chapter 19: The Ethics of Xenotransplantation


Chapter 19: The Ethics of Xenotransplantation


WHEN OUR ADVENTURES INTO SPACE allowed us to see our planet for the first time, we were gifted with the reality that we and other earthly creatures live on a beautiful blue globe turning slowly through space. This truth was evident: we inescapably live together. The science and technology that enabled this vision are increasingly connecting us further and in such a way that the impacts of environmental, political, economic, and military events in one part of our planet reverberate across all of it. What we do affects the Earth, which, according to James Lovelock (1979) in his Gaia theory, is a living
entity, too. Our planet appears to have entered a new epoch, the Anthropocene,¹ so named from the Greek word for “human” (anthropos) to indicate the negative effect humans are having on the systemic stability of the Earth (Clement, 2021). Along with the lives of other species, we are endangering our own existence, as our planet’s stability is necessary to human health and flourishing.

Our greatest problems—the paramount threats to our survival as individuals, as communities, and even as a species—are global ones: the effects of human activities on the environment and increasing climate change; emerging and resurgent infectious diseases; terrorism; nuclear and biochemical weaponry; and for many, devastating poverty. While our modern sense of “ethics,” from the Greek ethos for “way of living,” is about how one should live, it is imperative that we recognize that it is essentially about how we should live together. A morally imaginative shift to a planetary perspective must occur, one in which global solidarity is created, appalling inequities are diminished, and actions that sustain life are actively pursued (Benatar et al., 2003; Benatar & Brock, 2011). The philosopher Peter Singer warns in his work One World: The Ethics of Globalization (2002) that our survival may depend on “how we respond ethically to the idea that we live in one world” (p. 13).

Active recognition of our global reality has been with us at least since the 21st century began. As a nurse, and as an academic, in 2001 I began to consider how this reality affected the ethics of nursing practice—including the role of human rights as the moral underpinning of global relations—through writing about it (Austin 2001a, 2001b). I continued to publish on the topic (Austin, 2004, 2008, 2016), including my chapter in the first edition of Toward a Moral Horizon: Nursing Ethics for Leadership and Practice (Austin, 2003).

In this chapter, I provide advanced practice nurse leaders with key concepts significant to global health ethics and discuss its interface with human rights. The current state of global governance for health—and the possibilities and predicaments of expanding one’s professional health care responsibilities to embrace the entire world—are explored. I will reference the SARS-CoV-2 pandemic throughout the chapter, given that this deadly viral threat has made our global interconnectedness so evident.
Essential Values of Global Health Ethics

To start, I will explore various values essential to health care ethics that need to be enacted: human dignity, social solidarity, social responsibility, social justice, and health equity. The central value—human rights—is delineated, and a framework for global health governance is shared.

Human Dignity

The belief that human beings possess an inherent dignity existed in classical philosophy, such as that of the Roman statesman Cicero in his *De Officiis* ([On Duties] (44 B.C.E./1913), and was based on the human ability to reason and the possession of free will. It was not until Immanuel Kant’s *Groundwork for the Metaphysics of Morals* (1785/2018), however, that human dignity was systematically addressed as a principle relevant to ethics and law. For Kant, the ability to reason meant that we are capable of living an ethical life (Lutz-Bachmann, 2018). A contemporary conception of human dignity, evolving in the twentieth century, closely links human dignity with rights and casts it as the primary assumption underlying our modern conception of human rights (Sensen, 2011). This understanding includes the idea that, as human dignity is innate to the human condition, it is equally possessed by all and cannot be legitimately denied (Adorno, 2009).

In the Preamble to the *Universal Declaration of Human Rights* (UDHR) (United Nations General Assembly, 1948), it is stated that the inherent dignity of all members of the human community (as well as their equal and inalienable rights) “is the foundation of freedom, justice and peace in the world.” Article 1 claims that “[a]ll human beings are born free and equal in dignity and rights” (United Nations General Assembly, 1948). The significance of human dignity is noted across most human rights documents, as well as treaties that ban maltreatment and injury such as slavery, torture, or discrimination. Connecting dignity with rights is imperative as, while human dignity justifies human rights, it is rights which can be legally addressed and protected (Adorno, 2009).
As we share the Earth with other living things, we will need to move beyond respect for only human dignity. The German philosopher and theologian Albert Schweitzer (1875–1965) believed that we are ethical only when all life is sacred to us, not only the lives of our fellow humans. For Schweitzer, ethics was about reverence for life: an understanding, he acknowledged, that “throw[s] upon us a responsibility so unlimited as to be terrifying” (1946, p. 254).

**Social Solidarity**

Social solidarity is the felt sense of belonging to a group or community, united in shared characteristics or common goals, such that a level of interdependence is recognized and a feeling of unity created. It is a “fellow-feeling” that can motivate “we-thinking” and readiness for mutual support (Davies & Savulescu, 2019, p. 134). Social solidarity is active; it is not simply an attitude. A catalyst for solidarity can be recognition of shared vulnerability (West-Oram, 2020); thus, our inherent human vulnerability potentially offers hope for achieving global solidarity. The United Nations (UN), whose very existence is emblematic of solidarity, is evidence of a global willingness to strive for community. It has designated December 20th as International Human Solidarity Day to emphasize the concept’s importance. As the UN’s Millennium Declaration (United Nations General Assembly, 2000) describes:

> We recognize that, in addition to our separate responsibilities to our individual societies, we have a collective responsibility to uphold the principles of human dignity, equality, and equity at the global level. As leaders we have a duty therefore to all the world's people, especially the most vulnerable and, in particular, the children of the world, to whom the future belongs. (Value and Principles 2)

Solidarity, involving both rights and obligations (Davies & Savulescu, 2019), plays a major role in any nation’s ability to successfully address a crisis. A sense of global solidarity prompted the UN member states to first adopt the Millennium Development Goals to reduce poverty by 2015 and then, in September 2015, to build upon...
these goals by adopting a 2030 agenda for sustainable development (UN Department of Economical and Social Affairs [UNDESA], 2015) with 17 goals (see Box 15-1). Every four years, the UN publishes a Sustainable Developments Goals report, created by a group of 15 independent scientists from various disciplines and institutions selected by the Secretary-General. At the time of this book’s publication, the latest report was The Sustainable Developments Goals Report 2021 (UNDESA, 2021a). Table 20-1 names the UN’s 17 sustainable development goals (SDGs) (UNDESA, n.d.).

### Table 20-1

<table>
<thead>
<tr>
<th>Goal</th>
<th>Description of Goal</th>
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<tbody>
<tr>
<td>1</td>
<td>no poverty</td>
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<tr>
<td>2</td>
<td>zero hunger</td>
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<tr>
<td>3</td>
<td>good health and well-being</td>
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<tr>
<td>4</td>
<td>quality education</td>
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<td>5</td>
<td>gender equality</td>
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<td>6</td>
<td>clean water and sanitation</td>
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<td>7</td>
<td>affordable and clean energy</td>
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<td>8</td>
<td>decent work and economic growth</td>
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<td>9</td>
<td>industry, innovation and infrastructure</td>
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<td>10</td>
<td>reduced inequalities</td>
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<td>11</td>
<td>sustainable cities and communities</td>
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<tr>
<td>12</td>
<td>responsible consumption and production</td>
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<tr>
<td>13</td>
<td>climate action</td>
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<tr>
<td>14</td>
<td>life below water</td>
</tr>
<tr>
<td>15</td>
<td>life on land</td>
</tr>
<tr>
<td>16</td>
<td>peace, justice and strong institutions</td>
</tr>
<tr>
<td>17</td>
<td>partners for the goals</td>
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</table>

The global importance of solidarity became dramatically evident during the SARS-CoV-2 pandemic, with the recognition that the virus must be stopped everywhere if it was to be stopped at all (Mishra & Rath, 2020). Unprecedented collaboration among medical researchers across national boundaries achieved nearly miraculous results in the creation of new SARS-CoV-2 vaccines. The worldwide initiative COVID-19 Vaccines Global Access (COVAX)—led by the partnership of the World Health Organization (WHO),
Gavi (the Vaccine Alliance), and the Coalition for Epidemic Preparedness—was created in 2020 to accelerate the manufacturing of vaccines and ensure equitable global access to them. As I explain below, this initial solidarity response proved, however, to be fragile.

This pandemic presented an opportunity to address the usual exclusion of ethics in the distribution of vaccines due to factors such as the prioritization of profit by pharmaceutical companies and the valuing of life more in some countries than others (Binagwaho et al., 2021). COVAX provided guidelines titled *Fair allocation mechanism for COVID-19 vaccines through the COVAX Facility* to support equitable access to vaccines worldwide (COVAX, 2020). Ideas from bioethicists—such as a vaccine lottery once the “at high risk” were vaccinated—buoyed these efforts (Jecker et al., 2021). Overall, however, ethics did not prevail.

Many vaccine manufacturers refused to engage in the principles of global solidarity. They declined to share knowledge and technology that would have significantly increased vaccine production and availability. Some high-income countries (including many provinces in Canada) provided booster shots for fully vaccinated people at a time when less than five percent of Africans were vaccinated (Moeti, 2021). In an August 12, 2021 article in *Time* magazine, Dr. Adhanom Ghebreyesus, Director-General of the WHO, noted that this situation must make health workers in low-income countries wonder about the meaning of “solidarity.” The reality is that solidarity can require sacrifice to ensure that others are receiving what they need—and such sacrifices may not be forthcoming.

**Social Responsibility**

Responsibility is defined as “a moral obligation to behave correctly towards or in respect of a person or thing” (“Responsibility,” 2021). Social responsibility is grounded in the belief that actions at all levels of society—from individuals to communities to governments—should be such that a society’s well-being is supported and not harmed. Does this concept hold when the society is global in its magnitude? The answer depends on one’s point of view.

Those with a cosmopolitan perspective view all humans as citizens of the world, to whom they have a moral duty that is not
limited by proximity nor national boundaries. For instance, Peter Unger, author of *Living High and Letting Die* (1996), argues that giving up one's luxuries to help those who are suffering is essential to living an ethical life. The anti-cosmopolitan, statist perspective is that moral obligations are local and specific, delimited within a community or nation (Toumi, 2014). This is congruent with Rawls’s (1971) isolationist theory of justice: National self-determination should be the norm, and other nations must decide their own future. While anti-cosmopolitans see peaceful coexistence as a morally worthy goal (Stapleton et al., 2014), at the core of the philosophy is the belief that morality is always local. In this schema, cosmopolitanism is viewed as impractical and undesirable. Attempts to realize universal values are unjustified, as they are an imposition of one's own account of “the good society” upon others.

Iris Marion Young (2006), an American political theorist and sociologist, developed a social connection model of responsibility and justice based on her belief that “[t]he social relations that connect us to others are not restricted to nation-state borders” (p. 106). She believes that we bear responsibility for structural injustices when our actions contribute to processes that create such outcomes. While such actions are morally distinct from deliberately committing an injustice, a shared responsibility now exists for us all, derived from social connections. This responsibility must be discharged through collective social action. Young offers a guide to determine how one might choose to act in accordance with this responsibility. I will adapt and apply her model to the roles of nurses and their ethical responsibilities for global health later in this chapter.

In a truly global society, social responsibility encompasses all of humanity, and ultimately all living things. Zygmunt Bauman captures, in his *Postmodern Ethics* (1993), the overwhelming scope of our moral responsibility, describing it as “cumbersome, incapacitating, joy-killing,” and “insomnogenic” (p. 242). The philosopher Ann Harbin (2014) acknowledges, too, how disorientating and unsettling complex responsibilities requiring moral action can be, especially when one is uncertain that a sufficient response is possible. She reassures us by noting that if one addresses projects suitable to one's capabilities, then there can be a meaningful response to calls to act. This is good advice for
advanced practice nurse leaders and other health care practitioners, given their roles and responsibilities for global health. Ethics in Practice 20-1 below illustrates the importance of engaging one’s moral imagination to create a meaningful response to global health issues.

**ETHICS IN PRACTICE 20-1**

*A Pressing Need to Engage Our Moral Imagination*

For nurses to embrace a global vision of nursing, we need to reflect upon our collective ethical responsibilities within the global community and reimagine health, nursing ethics, and health care ethics. This will be challenging. Benatar (2005) has identified moral imagination as necessary to a meaningful response to global health issues. Among other influences—such as a focus on technologies and narrow approaches to global health rather than attention to the social determinants of health—Benatar notes that concern for others’ severe ill health is not sustained when they are “anonymous and out of sight” (p. 1207) and therefore, perhaps, of less value to us. In a research project funded by the Canadian Institutes of Health Research, the Canadian Program of Research on Ethics in a Pandemic (CanPREP), it was found in a focus group study that economic and humanitarian discourses are evident when the scenario involves an outbreak originating in a low-income country. However, when the outbreak originates in Canada, a dominant response is to keep all resources for Canadians (Thompson et al., 2015). This type of response can be seen in the SARS-CoV-2 pandemic. Nurses are not immune to such a local viewpoint, despite our knowledge that the virus must be eradicated across the globe for Canadians to be safe in turn. Our moral imagination will be necessary to allow us to respond locally in ways that also sustain the global community.

**Social Justice**

Social justice, “the fair distribution of society’s benefits and responsibilities and their consequences” (Canadian Nurses Association, 2010, p. 10), is viewed by the United Nations (UN) as essential to the peace and security of nations. It is further strengthened by the existence of human rights and fundamental freedoms. The notion of “justice” is an ancient one. Confucius (551–479 B.C.E.) is said to have viewed justice as a principle of government and social conduct, as well as an essential virtue.
(Duvert, 2018). His view was congruent with that of Plato (428/427–348/347 B.C.E.), who considered justice a duty of the soul that made an individual good and a society harmonious (Bhandari, 2004). While their perspectives seemingly encompass a broad idea of social justice, the reality is that it was not until the late 18th century that fair distribution of benefits to all members of society began to be envisioned by philosophers like Thomas Paine (1791/1998), the author of The Rights of Man.

Social justice—that is, justice for the whole of society—is a contemporary idea that involves the fair allocation of resources and burdens among all. This aspiration has yet to be fully embraced, though the UN designated the World Day of Social Justice in 2006. In fact, the platitude “the rich get richer and the poor get poorer” is essentially true in today’s global community (UN, 2006, p. 1). The World Social Report 2021 (UNDESA, 2021b) reveals that there are 1.3 billion people living in multidimensional poverty, half of whom are children and 105 million of whom are aged 60 or older. Most of the world’s wealth (84%) is held by 10% of the global population; the other 90% share the remaining 16% of wealth. An even closer look reveals that one percent of humans inhabiting the Earth hold over a third (37%) of the world’s wealth (Capeheart & Milovanovic, 2020).

To help ameliorate this inequality, The World Social Report 2021 includes a reconsideration of rural development and a 2030 Agenda for Sustainable Development. The need to do so is urgent, given that four out of every five people who face extreme poverty live in rural areas. Many of these areas are experiencing depletion and degradation of natural resources to a severe extent, contributing to climate change and the occurrence of zoonotic diseases, such as COVID-19. “The current strategies and patterns of rural development are failing to meet either the socioeconomic or the environmental Goals of this Agenda” (UNDESA, 2021a). Rural development can be reset to achieve sustainability if it is moved to the centre of attention, instead of being an aside for urban development. Rural inequality can be overcome using ways that preserve the environment, such as “leveraging investments in public services and rural infrastructure while protecting the health of the planet” (UNDESA, 2021a, p. 1).
Health Equity

Health equity, a component of social justice, is described by the World Health Organization (WHO) as “the absence of unfair, avoidable and remediable differences in health status among groups of people” (2021a, p. 2). It is achieved when everyone can attain their potential for health and well-being. Canada is a healthy nation, but there are inequalities across our country that impact health and require remediation. In 2012, Canada, with other WHO member states, endorsed the *Rio Political Declaration on Social Determinants of Health* (WHO, 2021c), pledging action to promote health equity. The report *Key Health Inequalities in Canada: A National Portrait* (Public Health Agency of Canada, 2018) is a response to that pledge. Health inequalities were revealed to be persistent; some are even increasing. These inequalities primarily affect those with lower socioeconomic status, Indigenous Peoples, sexual and racial/ethnic minorities, immigrants, and people living with functional limitations (such as physical or mental impairments). The Health Inequalities Data Tool (Government of Canada, 2021a) is an online interactive database documenting Canada’s health inequality by province or territory.

Across the globe there are twice as many COVID-19 cases and deaths in deprived areas, such as communities with few resources who do not have access to quality health care services or to information from the internet (for example, information about how to stay safe or how to overcome obstacles in obtaining COVID-19 related aid) (WHO, 2021a). Those who are socially excluded, such as those who are unhoused or migrants, are at higher risk. Further evidence of health disparity exists. On April 1, 2021, it was noted that 86% of the half billion vaccines administered were in high-income countries; 0.1% in low-income countries (WHO, 2021a). As noted previously, some high-income countries were already offering a third dose of the vaccine to people who were fully vaccinated in October 2021. In Ethics in Practice 20-2 below, disparities in health equity related to maternal health care are explored.
ETHICS IN PRACTICE 20-2

Health Inequity Revealed in Maternal Mortality Rates: Ghana and Canada

In 2017, the maternal mortality ratio in Ghana was 308 deaths per 100,000 live births, gradually falling from 398 deaths per 100,000 live births in 2003 (World Data Atlas, n.d.). In 2018, the Canadian maternal mortality rate was 8.3 deaths per 100,000 live births (Statistics Canada, 2019). A possible cause of this significant discrepancy may lie in the level of available resources. These resources are limited, for example, in northern Ghana, as described by Boakye in her 2021 University of Toronto PhD research study, Analysis of the Moral Habitability of Obstetric Settings in Ghana, of three tertiary maternal wards in the region. A critical moral ethnography study, the research involved 30 nurses and midwife participants. Brief excerpts from descriptions by the study’s nurse participants follow.

The maternity ward is “characterized by a lack of space and beds, resulting in the admission of patients on the floor and chairs, bed-sharing, and in some instances, patients being denied admissions.” A nurse reveals, “We don’t have oxygen to save life. The predominant role of a hospital is to save life” (Boakye, 2021, p. 98). She says that the ward can be without oxygen for two or three months, but “never do we hear that the hospital car did not have fuel to pick up the CEO [Chief Executive Officer] on his rounds (p. 98).” Another nurse shares that “[t]here are occasions whereby two patients need mechanical ventilation at the same time. There is no way we can actually take the ventilator from one … hmm actually is a hard decision to take” (Boakye, p. 99). This nurse describes how, if a search for a ventilator in the main ICU fails, “you only fold your arms and see the patient go [slow tone]” (Boakye, p. 99).

Practice for nurses and midwives in these wards exists in “a context dominated by the scarcity of resources, overwhelming and incoherent moral responsibilities, oppressive conditions, and workplace violence” (Boakye, p. 2). These factors constrain their capacity to meet their caring responsibilities and endanger the lives of patients. The suffering and distress these conditions provoke is experienced not only by the patients, but by those struggling to give them care and keep them safe.

Human Rights and Global Governance of Health Human Rights

Uniting and supporting all of the values covered above—human dignity, social solidarity, social responsibility, social justice, and health equity—is a central, encompassing value: human rights. Human rights are grounded upon the assumption that every human being is born free and equal in dignity and rights. John Locke, the
17th-century English political philosopher, argued that—contrary to his contemporaries’ claims that people are, by nature, subject to a monarch—people are free, equal, and possess natural rights (i.e., right to life, liberty, and property). He further stipulated, in his Second Treatise of Government (2003/1690), that these rights exist independently of the laws of any society. For Locke, a nation’s government exists by the consent of its people in order to protect their rights and promote the public good. The people, in turn, transfer some of their rights conditionally to their government and may, in turn, demand a new government if the existing one fails to meet its social contract with them (Tuckness, 2020).

In the 18th century, another English philosopher, the utilitarian Jeremy Bentham, strongly disagreed with this notion of natural rights. He decried them as devoid of meaning, as “nonsense upon stilts.” Rights are created by civil law, he argued, rather than being a condition of birth. Bentham remarked that we might wish inherent rights existed, but just as “want is not supply,” “hunger is not bread” (Waldron, 1987, p. 53).

The dispute regarding the legitimacy of human rights continues today. A contemporary argument, for instance, is made by Sim (2020), who finds rights conceptually confusing and inadequate. He believes that the concept of rights does not contribute much to moral decision making in bioethics and, while possibly useful in the expression of a moral concern, adds little to the understanding of it. Rights, he argues further, may cause moral reasoning to be passed over. However, health care practitioners, for the most part, appear to find human rights to have meaning in practice. Most would agree with Albert Einstein: “The existence and validity of human rights are not written in the stars … [They] have been conceived and taught by enlightened individuals in the course of history” (French, 1979, pp. 305–306).

Proponents of human rights frame health as an entitlement, not as a commodity. Human rights are informed by ethical principles, which, in turn, enhance the significance of global health ethics. A major distinction between human rights and ethical principles lies in the fact that rights are now a matter of law (WHO, 2015). In 1946, the WHO’s constitution was adopted, creating a fundamental right of individuals to the highest attainable standard of health. Soon after,
in 1948, the UN assigned its member states the responsibility of upholding the entitlements of their people claimed in *The Universal Declaration of Human Rights*, the world’s most translated document. Health as a right is described in Article 25:

> Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

> Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection (United Nations General Assembly, 1948, Article 25)

In other words, there must be equal opportunity of access to health care regardless of factors such as race, gender, economics, and geographical location. Upholding this right can be challenging for many nations, including Canada, with its remote communities in the far North. Our government acknowledges that inequities in access exist for Indigenous communities and that greater efforts are required to ensure Indigenous control over the design and delivery of their health services (see Ethics in Practice 20-3).5

The human rights paradigm is powerful in its individual and global reach, allowing persons to claim particular rights without nationality being a factor (Gable, 2007). The UN’s system of rights (declarations, conventions, covenants) legally binds signatory states. Member states of the UN who have ratified agreements to uphold particular rights are assessed every four or five years to determine their progress in upholding these rights.6 Canada’s performance assessments and reports to the United Nations are freely accessible on the Internet. Table 20-2 lists various UN agreements to which Canada has agreed to be held accountable.7 For a full list of the UN’s human rights documents, see the UN Office of the High Commissioner Human Rights (OHCHR; n.d.).
The Declaration of Bioethics and Human Rights

The UN’s Universal Declaration of Bioethics and Human Rights (UDBHR) is a global document grounded in the reality of human connection and directly related to ethics and human health. It was adopted by the UN’s Educational, Scientific, and Cultural Organization’s (UNESCO’s) General Conference on October 19, 2005 (UNESCO, 2005). In this declaration, the principles of bioethics are presented within a human rights framework. The UDBHR goes beyond protection of individual rights to emphasize the solidarity of the human community, and the equality of all humans in relation to dignity, justice, and rights. The need for pluralism and diversity to be respected is stipulated, as is the need for protection of the environment (Langlois, 2014). Specific goals for universal access to
essential medicines and quality health care, as well as the sharing of science and technology, are noted.

The declaration was welcomed as an accomplishment by many, given that it appeals to human dignity, but combines this appeal with a practical, global recourse to human rights (Adorno, 2009). The profound doubts of those who wonder whether the declaration can have a meaningful impact, given that it is nonbinding under public international law, does not diminish its worth for the non-governmental agencies and health professionals whose work it informs and supports (Faunce & Nasu, 2009).

As the health of human life on Earth is increasingly threatened—with the attendant potential negative effects on other living things rising in equal measure—the human rights paradigm provides advanced practice nurse leaders, as well as other health care professionals and policymakers, with a guide to a meaningful response. It offers them the means to provide a more just allocation of health care resources while respecting human dignity and the necessary ethical constraints of informed consent and confidentiality (Frenk & Gomez-Dantés, 2021). The following Ethics in Practice scenario summarizes the story of a compelling violation of human rights.

**ETHICS IN PRACTICE 20-3**

*The Story of Joyce’s Principle*

In September 2020, Joyce Echaquan, a 37-year-old Atikamekw woman and mother of seven from the Manawan reserve in Quebec, was admitted to the hospital in Joliette, Quebec for stomach pains potentially related to her heart condition. Two days later, as Joyce was dying, she recorded her final moments on her phone for Facebook Live. The recording revealed hospital staff insulting and swearing at her as she cried out for help. This horrific scene made national news in Canada. Hospital staff were fired and calls for ending such discrimination, which is prohibited under the *Canadian Human Rights Act* (Government of Canada, 1985), came from across the country (Banerjee, 2021). The Canadian government, based on dialogue with Joyce’s family, leaders, and practitioners from both her own Indigenous community and Indigenous communities across the country, as well as government representatives and health system partners, funded the development and implementation of Joyce’s Principle (Council of the Atikamekw of
Manawan & the Council de la Nation Atikamekw, 2020). Joyce’s Principle “aims to guarantee all Indigenous Peoples the right to equitable access to social and health services, as well as the right to enjoy the best possible physical, mental, emotional and spiritual health” (Indigenous Services Canada, 2021). These words were inspired by Article 24 of the United Nations Declaration on the Rights of Indigenous Peoples (UN Department of Economic and Social Affairs, 2007), which sets out, among other rights, “the right to access, without any discrimination, to all social and health services.” The application of Joyce’s Principle is one means to promote ethical health care for the Indigenous Peoples of Canada.

Health for All: The Role of Global Health Governance

To achieve “health for all,” guidance and leadership at a global level are required. Global health governance can be defined as “governance that involves the structural and normative aspects of managing the determinants and outcomes of global health,” with human rights playing an integral role (Gable, 2007, p. 534). A global government has yet to come into being, although over the past three centuries, joint efforts have evolved to address health issues that reach beyond national boundaries. These efforts began with international standards for sanitation and trade-related health issues. Additionally, non-governmental agencies were created to respond to emergencies and conflicts (e.g., the International Federation of the Red Cross and Red Crescent Societies, commonly known as the Red Cross). Such agencies evolved into institutions formed at the end of World War II in hopes for a better world (e.g., the World Bank [1944]; the United Nations [1945]). Since 1948, the WHO has been the primary institution with normative and legal authority over global health, setting the agenda for addressing urgent health crises. The World Health Organization has an online “health emergencies list” that notes disease outbreaks, disasters, and humanitarian crises where the organization has a role in supporting nations to respond and recover (WHO, n.d.).

Such crises are set to escalate, according to warnings from other global organizations such as the World Economic Forum (WEF) (Sridhar & Gostin, 2014). The WHO identifies these crises as: (a) the
climate crisis; (b) health care delivery in conflict/crisis areas; (c) health care equity; (d) access to treatment; (e) infectious disease/pandemic prevention; (f) unsafe products; (g) underinvestment in health workers; (h) adolescent safety; (i) threat of anti-microbial resistance/access to low-cost medicines; (j) health care sanitation; (k) the need to improve the public trust in health workers; and (l) capitalizing on technological advancements (Advisory Council, WHO, 2020).

In addition to WHO, there are other UN organizations that develop independent institutional policies and programs to address health within their respective spheres of influence. These include the UN International Children's Emergency Fund (UNICEF), which advocates for ways to give children a good start in life; the United Nations Development Program (UNDP), which helps countries eradicate poverty, decrease inequalities and exclusion, build resilience, and achieve the UN’s Sustainable Development Goals; and the United Nations Population Fund and Activities (UNPFA), which focuses on reproductive health (Meier et al., 2020).

Given that health is a factor across critical areas of government from foreign and security policy to trade agreements, health diplomacy plays a large role in the endeavours of the World Health Organization. Indeed, in our interdependent world, health challenges require cooperation of nations through political negotiations and solutions. Such discussions take place at the World Health Assembly, the Human Rights Council and, at times, the UN General Assembly (WHO Eastern Mediterranean Regional Office [EMRO], 2021).

The SARS-CoV-2 pandemic has exposed our need for radical global solidarity if solutions are to be created and humanity’s survival is to be ensured. Achieving harmonized action on this deadly threat has promise for facilitating meaningful response to other perils, such as climate change (Taghizade et al., 2021). The UN’s Conference of the Parties (COP), who have signed the United Nations Framework Convention on Climate Change (UNFCCC; United Nations, 1992), a treaty in force since 1994, meets every five years. In November 2021, (delayed one year due to the SARS-CoV-2 pandemic), the UN Climate Change Conference (COP26) was held in Glasgow to assess progress since the 2015 Paris Agreement and to
repledge to increasingly ambitious climate goals. Given the enormity of the consequences if global temperatures rise to two degrees Celsius or more above preindustrial levels, COP26 was viewed as highly critical not only to global health, but to the globe itself. Representing Canada, Prime Minister Justin Trudeau pledged to meet these climate goals:

- price on carbon, currently $40 per tonne, to rise to $170 per tonne by 2030;\(^8\) cap on oil and gas emissions with goal of net-zero by 2050;
- global methane pledge to lower emissions 30% below 2020 level by 2030;
- protecting 25% of Canada’s land and oceans by 2025 (Vasquez-Peddie, 2021); and
- net-zero emissions in Canada’s electricity grid by 2035 (Government of Canada, 2021b)

In addition to government agencies, and other organizations that were created to improve global health, public-private collaborations are being developed in an attempt to address global inequities.

**Public-Private Collaborations: The World Economic Forum**

The World Economic Forum (WEF), was created in 1971 as a not-for-profit foundation. Headquartered in Geneva but best known for its annual meeting in Davos, Switzerland, its aim is to leverage entrepreneurship in the global public interest while staying grounded in the values of moral and intellectual integrity. It has centres dedicated to addressing various areas in the business world, including (a) industry transformation; (b) media, entertainment, and sport; and (c) the mobility of people and goods. Past achievements include the 1988 Davos Declaration (in which Greece and Turkey agreed to reduce tensions), and the 1995 meeting of national trade ministers that eventually led to formation of the World Trade Organization (WTO) that same year.

WEF has various platforms, including a “Platform for Shaping the Future of Health and Healthcare.” One focus of this platform is that of global health, with such areas of interest as global health governance, data collection and communication, health and
climate change, and preparing for pandemics.\textsuperscript{9} Related health projects include the development of precision medicine (i.e., more personalized and targeted approaches) and genomic data policy.

The founder and executive chairman of the WEF, Klaus Schwab, co-authored a 2021 publication with Peter Vanham entitled \textit{Stakeholder Capitalism: A Global Economy That Works for Progress, People and Planet}. They stated that “stakeholder capitalism,” (i.e., capitalistic approaches by businesses and political leaders) should be the basis of the global economy and used to address world challenges, such as rising income inequality, the monopoly market powers of large corporations, and exploitation of natural resources (Schwab & Vanham).

The WEF is both highly influential and substantively criticized: it brings together political leaders, business leaders, and nongovernmental organizations to consider key world issues, but makes decisions without accountability to an electorate or to shareholders (Delivorias, 2016). The WEF appears to be based upon the belief that businesses do better at solving problems than do governments.

**The Global Elite**

According to Forbes, a new billionaire was created, on average, every 17 hours in 2021, with the world’s wealthiest altogether richer than the previous year by five trillion US dollars (Dolan et al., 2021). Members of this plutocracy tend not be from “old money”; rather, they are innovators and entrepreneurs who share a global perspective. Their sense of community with one another tends to be stronger than with people from their own countries (Freeland, 2011). Most of these innovators and entrepreneurs have at least one philanthropic foundation, which usually focuses on finding innovative ways to solve global problems and is often related to health. Journalists Bishop and Green, in their book \textit{Philanthrocapitalism: How Giving Can Save the World} (2008), note that the elites’ way of giving is strongly influenced by their way of doing business. In \textit{Winners Take All: The Elite Charade of Changing the World} (2018), Giridharadas states that billionaires use philanthropic giving to clean up their reputations—and avoid taxation. These actions may blur the reality that these richest humans in the history of the
world “own” the future (Giridharadas, 2018). Ethics in Practice 20-4 below describes some examples of the roles played by the ultra-rich in “fixing the world,” and introduces some questions about the implications of their actions.

ETHICS IN PRACTICE 20-4

The Role of the Ultra-Rich in Fixing the Health of the World

The global elite are said to be using their wealth to explore ways to solve world problems, particularly those related to disease and lack of access to the necessities of life. Bill Gates, for instance, is contributing to the Bill & Melinda Gates Foundation to find cures for the diseases killing millions of children in low-income countries.

Arrangements such as these raise a series of difficult questions. Is a wealthy person’s actions to prevent or cure a disease of their choosing the best strategy to improve world health? Would a better way be to donate the funds to WHO and contribute to a planned, needs-based global response? Wealth donation can make a significant positive difference in the health and well-being of lives around the world if it is informed by a genuine understanding of the targeted global problem.

A recent example of the potential discrepancy between the priorities and knowledge sets of the global elite and the health care establishment occurred in October 2021, when the UN World Food Program director, David Beasley, challenged the ultra-rich to help solve world hunger. Elon Musk, Time’s “Person of the Year” for 2021 and one of the wealthiest people on Earth, announced that he would sell US $6 billion of Tesla stock (2% of his wealth) and donate it to the UN, provided they could prove that the sum would solve world hunger. Beasley replied that it would not solve world hunger, but could save 42 million people from starving (Gollom, 2021).

In other words, while Musk’s financial donation could do much to address the immediate needs of those on the brink of starvation, the situation is also more complex. Global food insecurity is a longstanding problem, and one that requires comprehensive, integrated, and long-term responses. These responses might be difficult for non-professionals to foresee, assess, or accommodate.

The Roles and Ethical Responsibilities of Nurses in Global Health

The COVID-19 pandemic has revealed the worldwide need to ensure that nurses are supported in developing and sustaining their capacity to respond to this type of deadly public health threat while continuing to provide other essential health services (WHO, 2021b, p.
vi). The WHO’s _Global Strategic Directions for Nursing and Midwifery 2021-2025_ (WHO, 2021b, April 6) addresses the urgency of investing in these occupations and outlines strategic directions in four areas:

1. **Education**: to ensure that practitioners have the necessary attitude, knowledge, and competencies to meet national health priorities and that health systems’ need for their services is met or surpassed;

2. **Jobs**: to promote the creation and sustaining of positions for health workers, with effective recruitment and retention in place and international mobility and migration ethically managed;

3. **Leadership**: to encourage a substantial increase in the number and authority of nurses and midwives in senior health and academic positions and uphold continued development of the next generation of leadership;

4. **Service delivery**: to enable health workers to work to the full extent of their education and training in safe and supportive service delivery environments.

The report suggests that investments be made in strategic areas, such as overtime and hazard pay, safety measures (e.g., personal protective equipment and training), and mental health services. A critical global nurse shortage is identified in the report through findings indicating that 65% of UN member states have under 50 nurses/midwives per 10,000 population and that a needs-based shortage of 5.9 million nurses exists (WHO, 2021b, p. 11).

Gender disparity persists in top health management. In the global health workforce, 70% of health care workers are women. Within the nursing profession, 89% of nurses are female, as are 93% of the midwives. Nevertheless, only 25% of the senior roles in health organizations are held by women (WHO, 2021b, p. 15). As health is one of the highest priorities on the UN’s 2030 sustainable development agenda, the need for nursing and midwifery leadership is particularly pressing. Health organizations require nurses in senior roles, with accompanying input into organizational design. Nurse leaders are also needed in government departments, given the significant importance of health and health care throughout government policy (Catton & Iro, 2021).
Rosa et al. (2020) acknowledged that while the expertise of advanced practice nurses (APNs) can contribute significantly to achieving the Sustainable Development Goals, and to the promotion of universal health coverage, to date APNs are under-utilized in global health care. These authors maintain that expanding the scope of practice of nurse practitioners globally and making strategic use of nurse practitioners across nations is critical to global health. They note that education of interdisciplinary partners, policymakers, and the public regarding the capacity of APNs is required, as are appropriate role titles and remuneration reflective of this level of service.

Efforts are underway to realize this enhanced role for nurses. Programs such as the Global Leadership Mentoring Community of nursing organization Sigma Theta Tau International—in which mentors and mentees are brought together across seven global regions to promote leadership capacity, understanding of global issues development, and the building of networks (Rosser et al., 2020)—can contribute to the evolution of the role of APNs in global health. The Global Nursing Leadership Institute (GNLI) program of the International Council of Nurses (ICN) has the potential, as well, to facilitate an increase in the number of nurses in senior leadership roles (ICN, 2020, August 20). Notably, in the GNLI 2021, there was an emphasis on health disparities and on the impact of the SARS-CoV-2 pandemic on preparation of nurses for participation in local to global levels of policy actions.

While the need for enhanced participation and leadership from nurses on the global stage is clear, for many nurses, across all levels of practice, considering ethical responsibilities from a global perspective can be unsettling. Simply coping with the demands of everyday practice can be challenging, particularly within pandemic parameters. Nurses, however, understand and embrace ethical responsibilities in their nursing roles. What is required now is for nurses to develop a global state of mind: to understand local actions as situated within a global community. A global attitude has always been foundational to the health disciplines: the best care and treatment possible are to be introduced without discrimination to race, religion, political affiliation, enemy or friend status, or any such
attributes of recipients. Although the moral space is changing, the core values of nurses remain constant.

A helpful way to rethink ethical responsibilities related to the social roles of nurses is offered by the American political theorist and social feminist Iris Marion Young (2006). In her social connection model, she provides an answer to an important question: How do we choose the best ways to use our limited time, resources, and creative energy to respond to a challenge? For Young, the challenge is that of injustice; for nurses, our challenge will be related to health needs, as well. Each of us, as a nurse and moral agent, must decide for ourselves what we can and should do by considering our capacities, circumstances, and opportunities in relation to a need that we identify. The four areas that follow can be helpful in making such decisions:

- **Interests**: Where are your interests? What aspect of health, health promotion, or health care most interests you? Healthy communities? Family support groups? Research on a particular disease?
- **Power**: What potential exists for you to act on or influence processes related to your interests? Where does your capacity to encourage positive change lie? Soft power, such as having a voice or a particular form of influence? An ability to organize and get others involved? The capacity to provide insight or education on a health issue?
- **Privilege**: Are you privileged in some way? Can you make that privilege work to improve health or health care for others?
- **Collective ability**: Does your membership in a group or organization connect you to others so that you are able to act with them collectively?

Contemplation of these areas may assist you to identify how, as a nurse, the ethical responsibilities of this time may be met. The following Ethics in Practice situation gives an example of how a global threat can bring communities together.
A Global Threat Brings Us Together and Tears Us Apart

On March 16, 2020, a BBC News, Washington article by Tom Gerken appeared with the headline: “Coronavirus: Kind Canadians start ‘caremongering’ trend.” “Caremongering” describes a public movement, organized via social media, to arrange acts of kindness to members of one’s local community at the onset of the COVID-19 pandemic. Some examples of caremongering are delivering baby food to a single mom; grocery shopping for those particularly vulnerable to the virus; and providing gift cards to someone unemployed due to workplace closure. Such acts of kindness occurred across the globe, not only in Canada. Health care workers worldwide—despite potential severe risk to themselves and their families—did their duty by caring for those ill with the virus, and they received the world’s gratitude (Lane, 2020). Many cities set designated daily times for citizens to show their appreciation through cheering, singing, clapping, or pounding pots with a spoon.

Over time, however, a more disparate response emerged. Some reacted to the pandemic with scaremongering, not caremongering. In both low- and high-income countries, health care workers became targets of harassment, threats, and acts of violence (Bhatti et al., 2021; Cukier & Vogel, 2021). Health care practitioners, patients, and ambulances were prevented from entering and exiting hospitals (Rabson, 2021a). This threat was so significant that the Canadian government moved to amend its Criminal Code to specifically address it (Rabson, 2021b). Fear and anger were stoked by myths perpetuated via social media (e.g., the COVID-19 vaccine was created to control the population through microchip tracking; it alters DNA; or it causes infertility and miscarriages) (Mayo Clinic, 2021). This occurred despite the WHO’s efforts to provide clear, informative public advice on the vaccines and on getting vaccinated (WHO, n.d.). This information campaign was supplemented by a weekly video and audio series in which experts explained the science related to COVID-19 via the WHO’s YouTube, Instagram, Facebook, Twitter, and LinkedIn channels.

While the pandemic revealed to the world that solidarity was essential to our survival, it revealed, too, that achieving and sustaining a safe, collaborative global community will be a great challenge; a challenge we—and succeeding generations—must strive to accomplish.

Conclusion

Martin Luther King, Jr., in his last work, Where Do We Go From Here: Chaos or Community (1967), advises us that our “great new problem” is that we—“unduly separated in ideas, culture and interests”—must find a way to live peacefully together in a “world house,”
as “we can never again live apart” (p. 177). He tells us that “science has provided us with adequate means of survival and transportation, which makes it possible to enjoy the fullness of this great earth. The question now is, do we have the morality and courage required to live together … and not be afraid?” (p. 192). Perhaps what is most important is that we welcome this question and those that come with it: How do we live harmoniously together? How can we be responsible to and for one another? How do we cultivate the moral courage to live the answers? As the UN reminds us in their motto: *This is your world.*

**QUESTIONS FOR REFLECTION**

1. What elements of global health and global health ethics do you believe should be included in Canadian undergraduate nursing education? In advanced practice nursing education?

2. Imagine that you are a member of the ultra-rich global elite. Would you invest any of your wealth in endeavours to improve global health? If the answer is “yes,” how would you go about doing this? What would your focus be?

3. What, in your opinion, is the most pressing global health ethics issue today? Identify the factors that inform this choice.
Endnotes

1 The International Union of Geological Sciences, which names and defines epochs, has yet to formally approve “Anthropocene.”

2 “Gavi” comes from the full name, the Global Alliance for Vaccines and Immunization.


4 This involved a collaborative effort by the Pan-Canadian Public Health Network, the Public Health Agency of Canada (2018), Statistics Canada, and the Canadian Institute for Health Information in partnership with the First Nations Information Governance Centre. The resulting portrait of the state of health inequalities in Canada is available through the Health Inequalities Data Tool, an online interactive database. See Government of Canada (2021a).

5 Also see Chapter 5 in this book.

6 UN human rights instruments may not be ratified by a nation, even if initially signed (e.g., the United States signed The International Covenant on Economic, Social, and Cultural Rights in 1977 [under President Carter], but has never ratified it.

7 See Government of Canada (2020).

8 The proceeds are returned to provinces/territories meeting federal requirements; in Alberta, Saskatchewan, Manitoba, and Ontario, rebates are issued to citizens.

9 See https://www.weforum.org/platforms/shaping-the-future-of-health-and-healthcare

References


IN REFLECTING ON THE OVER 20 YEARS of working on three editions of this book, we acknowledge that the challenges nurses face in enacting nursing ethics in their practice are rooted in history and the contexts in which they practice. Over these years, while we have been at different stages of our professional careers, we have benefited from the insights of each other, our colleagues and students, and all those who have used our texts as learning and teaching tools. This third edition of our book builds on our cumulative insights from writing the two previous editions, as well as the knowledge we

“Nursing ethics is philosophically informed and robust. Nursing ethics is relational. Nursing ethics is contextual, rooted in experience. Nursing ethics is about the moral character of the nurse and the instantiation of nursing identity. Nursing ethics, rightly enacted, is an alloy of skilled nursing practice and ethical comportment; they are interfused and inseparable—one does not exist rightly without the other.” (Fowler, 2022, para. 7)
have acquired from our interactions with students and nurses, particularly advanced practice nurse leaders. These interactions, as well as our teaching, graduate supervision, and collaboration with other health care providers (HCPs), have enriched our understandings of the challenges nurses and HCPs face, and the need for nursing ethics to continue to flourish. Our goal in writing the three editions of this text has been—and continues to be—to promote ethical fitness, and to provide hope for all of us in the nursing profession, as well as for our colleagues in other health care fields.

The content of each of our three books has been influenced by specific events that occurred in the health care environment at the time of writing each edition. For example, in our first book, published in 2004, we described and analyzed the moral landscape, the moral climate, and the moral horizon for nurses in the wake of the 2003 severe acute respiratory syndrome (SARS) outbreak, where it became clear that the voices of nurse leaders were essential in order to ensure optimal care for all citizens (Registered Nurses Association of Ontario, 2003). When writing the second book in 2013, we included information about the effects of the aftermath of SARS on public health and noted the importance of the establishment of the Public Health Agency of Canada to coordinate the changes needed in primary health care.

When considering the issues nurses faced during the periods above, and the issues they face today, we are struck by the similarity to situations they faced during a prior pandemic, over a hundred years ago (Fowler & Gallagher, 2019). In 1919, there was evidence of a nursing and nursing student shortage, challenges with workloads for nurses, concerns about working conditions for nurses, concerns about the salaries of nurses, as well as widespread fatigue and exhaustion in the nursing workforce—all concerns that nurses continue to face today (Fowler & Gallagher).

**What We Have Offered in This Edition**

This third edition of the book has been created in the midst of a prolonged SARS-CoV-2 pandemic that has brought with it unprecedented changes in health care delivery and societal practices. The challenges of both this pandemic, and the many global
issues facing society, require the expertise of advanced practice nurse leaders locally, nationally, and internationally. These challenges include the global climate emergency, war and insurrection, escalating health care costs, limited access to health care, racism, social injustice and inequity, poverty, inadequate Indigenous health care, and a growing opioid epidemic. Although developments have been made by advanced practice nurse leaders and others, there continue to be major challenges in all areas of health care. These challenges are exacerbated by an escalating worldwide severe shortage of HCPs, particularly nurses.

A clear vision of nursing ethics is required to ensure that advanced practice nurse leaders, and all nurses and HCPs, are able to provide quality health care. What we offer in this edition of Toward a Moral Horizon: Nursing Ethics for Leadership and Practice is a wide view of nursing ethics. We trust that the content of this textbook will closely match the current needs of advanced practice nurse leaders, all nurses, and other HCPs. We are confident that the approach taken in the chapters in this text will be useful to readers.

There is considerable new content in this edition, particularly in relation to social justice and equity in health care. We explore Indigenous ethics and perspectives, decolonization of nursing and health care, ethnocultural contexts, racism, ethical concerns during pandemics, and the promises and perils of technological developments.

Ethical responsibilities in specific areas of practice are described throughout the book, including in mental health care, in the care of childbearing individuals and families, in supporting the moral agency of children, and in the care of older adults. Other critical areas of practice include attention to Indigenous health care, genetics and identity, the ethical challenges of home health care, caring for people with disabilities, and biotechnological developments in health care. There are variations on many other topics, some covered in previous editions of the book, which are enlarged upon and updated in this edition. These topics include ethical concerns in nursing education and nursing research, a palliative care ethic for nursing at the end of life, ethical issues in public health nursing, and global ethical challenges.
Throughout this text, ethical leadership is promoted, with a particular emphasis on widening the understanding of nurses about the nursing profession itself, and its fit with organizations and health care systems. To that end, we stress the importance of enhancing the moral agency of nurses, developing strategies to deal with the moral distress of nurses, fostering the moral resilience of nurses, and promoting greater equity in nursing practice.

Throughout this book, we have pressed for nurses to recognize and maximize their leadership with a goal of boldly moving toward future moral horizons. This requires that they recognize and support the values upon which Canada’s unique health care system is based. Further, since nurses face so many challenges in all aspects of health care, they need to engage in research activities and use research findings to consider revised and new approaches to various areas of practice. Importantly, as advanced practice nurse leaders move into the future, they must address the ethical challenges and opportunities that they will continue to encounter in their practice.

On the Horizon: Challenges and Opportunities

In 2013, in the closing chapter of the second edition of our book, we began with a quote from a nurse participant in our research study about the quality of practice environments (Rodney et al., 2002). The nurse participant emphasized the importance of having hope to improve nursing practice and patient care, telling us that “we have to have some hope. And so that’s how I look at it … I am in no way thinking that there’s not more work to be done. There definitely is. But I have seen successes and so I think it is possible” (p. 91). At that time, citing work done by nursing organizations, as well as findings from research conducted by ourselves and our colleagues, we noted the leadership we saw across many areas of nursing practice. More than 20 years later, as we write the third edition of our book, we continue to see strengths in nursing leadership, and we continue to have hope. We know that nurse leaders have the education and skills to influence change regarding organizational priorities, and to support interprofessional staff, patients, families, and communities.
Further, we have been inspired by the commitment and leadership from all nurses that we consistently witness, whether they are advanced practice nurse leaders, nurses on the front lines of patient care, or student nurses.

We also continue to see persistent challenges—challenges that are reflected in various chapters in this text. For example, authors in this book have exposed ethical issues and critiqued systemic failures in Canada’s mental health care delivery system, in long-term care, and in the care of Indigenous people. Further, in a number of places, authors have explored the moral distress that accrues for nurses who are unable to practice according to their professional standards, often because of systemic failures in health care delivery. Unfortunately, moral distress continues to be a problem for overburdened nurses and other HCPs. In this edition, we underscore the importance of fostering moral resilience, so that nurses and other HCPs are better prepared to understand and address their experiences of moral distress, and hence provide more effective care for individuals, families, and communities. In today’s health care environment, advanced practice nurse leaders are highly skilled in the clinical areas for which they are responsible, and can help to ameliorate moral distress.

Nonetheless, we also continue to be aware of the substantial—and escalating—health care organizational challenges that nurses face. These challenges reflect the major problems that continue to be evident in Canada’s health care system overall. As we note in this text, such challenges include a chronic shortage of nurses and other HCPs in an era of increasingly complex health care requirements and fiscal limitations. In particular, during the SARS-CoV-2 pandemic, the shortage of physicians and nurses, as well as limited access to primary health care, has become alarming, highly publicized, and politicized. Some solutions have been developed, such as increasing the number of university seats for nursing and medical students, and increasing the number of nurse practitioners across Canada, with the goal of providing more nurses and physicians and better access to primary health care for patients.

As a result of nurse, physician, and other HCP shortages, emergency departments in Canadian urban and rural centres often have to “pick up the slack.” Staff in emergency departments are
frequently overwhelmed with increased patient loads. These patients often have not had health care from primary HCPs in their communities. Such gaps in health care delivery also threaten Canada’s cherished publicly funded health care system because they open the door for private health care options (Duong, 2023a). While there are some potentially equitable and effective alternatives emerging, such as a rise in virtual health care, multidisciplinary clinics, and hospital-at-home programs (Duong, 2023b), widespread initiatives to better support health care delivery across Canada are clearly needed.

Given the persistent challenges in health care delivery we have noted in this text, it behooves nurses and other HCPs to sharpen their political acumen at all levels of the health care system (micro, meso, and macro) so that they are able to work together to promote greater equity and effectiveness in health care planning and delivery. To actualize a robust, publicly funded health care system in Canada, advanced practice nurse leaders, all nurses, and other HCPs must work collaboratively to influence change, ensure sustainability, and promote equity in the system. The public they care for deserves access to their combined commitment and expertise.

**Charting Our Course**

Given that the public continues to place nurses at a high level of trust and respect (Canada’s Most Respected, n.d.; National Nurses United, 2023), nurses are well-positioned to take greater leadership roles in order to restore, maintain, and continue to develop what is beneficial in health care. Nursing practice must be grounded in nursing ethics. Therefore, the primary focus of nurses must be to engage in ethical practice in their work. Ethics must be embedded in all aspects of practice, and it must be the lens through which decisions are made and actions are taken. Nurses must continue to shape and adopt changes that need to occur for both present and future improvements. In addition, continued recognition must be given to the development and the increased complexity of professional roles for all nurses, particularly for advanced practice nurses.

At a time when health care needs are outstripping resources for care, governments must undertake urgent action and coordination
to attract more nurses to and across Canada. Recruitment of nurses must involve federal, provincial, and territorial governments, as well as nursing associations and organizations. This means that these groups must work together in fulfilling the recruitment of nurses, with an emphasis on striving to make sure that the knowledge and skills of nurses serve the current health care needs of Canadians.

Canada’s unique approach to health care is based on a publicly funded health insurance program. A sound knowledge about how health care is delivered in Canada, and the continuing commitment to provide access to health care for all Canadians, is vital for nurses. Nurses must understand this system and engage in political action to ensure that their voices are influential in effecting positive change in health care planning and delivery.

Some of the most pressing challenges facing Canadians today continue to be rooted in systemic inequities, yet many health care organizations have been unable to change their practices in order to eliminate these inequities. During the SARS-CoV-2 pandemic, the energy for and commitment to addressing inequities in health care delivery faltered. National and regional political action is critical to effect change in health care delivery, and nurses must be involved in helping to lead actions fostering such change. Our hope is that physicians, nurses, other HCPs, health care organizations, associations, and governments will continue to find ways to collaborate to meet the health care needs of Canadians.

When nurses engage in political action individually and collectively, they need to be very clear about priorities regarding whom they serve—that is, people requiring care, rather than governments and politicians. By keeping this focus in mind, nurses can make a major difference in the lives of Canadians. For example, Bernadette Pauly (a colleague and chapter author in this book from the University of Victoria), in her advocacy and policy development in Victoria for over a decade, has helped to preserve and enhance the lives of many homeless people and people with addictions. As another example, Elizabeth Peter (a chapter author in this book, and a colleague from the University of Toronto), has worked tirelessly to raise the profile about changes needed for home care in Canada. In her research, she describes how home care nurses sig-
nificantly influence the people in their care through education, role modelling, and restructuring the home environment.

Looking to the future, nurses ought to include a more purposeful linking of ethics with politics in order to promote the well-being of individuals, families, and communities. As cost constraints continue to proliferate in health care delivery, there are serious concomitant challenges to the moral agency of nurses and other HCPs. Therefore, nurses must continue to examine their values and ethics, and consider how to enact them in a Canadian democracy that is founded on an egalitarian ideal and where diversity ought to be respected.

Nurses need to be thoughtful and careful as they chart a course in current and future socio-political climates. This will require policy work at many levels, and political action in communities, workplaces, governments, and professional organizations. Working with provincial and national nursing associations will be foundational to charting the way forward. Nurses will need to consider comprehensive strategies to increase the number of nurses in Canada. Throughout, they must take significant political leadership in working with organizations to promote progressive change. Such progressive change requires that nurses come together to commit to a consistent set of values, such as those expressed in the 2017 Canadian Nurses Association (CNA) *Code of Ethics for Registered Nurses*.

When the CNA revised their *Code of Ethics* in 2017, they undertook a bold move by preparing a more broadly based code of ethics that also gave greater attention to social inequities. This revised *Code of Ethics* continues to provide guidance for nurses today. In Part II of the *Code of Ethics*, the focus is on ethical endeavours, where attention is directed to the social determinants of health and the need for primary health care, health promotion, and greater attention to vulnerable populations and global health. Nurses are encouraged to recognize the broader context of health, as well as the social injustices apparent in many aspects of health care. They are viewed as having responsibility for social injustice because they may contribute through their actions to the social processes and rules which bring about these injustices. Nurses need
to accept the responsibility to work individually and collectively to right the wrongs they witness.

Throughout this book, emphasis has been placed on the importance of relational ethics and the moral agency of nurses. From a relational standpoint, moral agency can be conceptualized as a collective good. Nurses need to consider and enact their moral agency to bring about positive changes to health care and to improve the health of the people with whom they work.

Nurses are positioned more effectively than ever before to take leadership roles, maintain what is beneficial in health care, and shape the changes that need to occur in the future. All the authors who have been involved in the writing of this third edition of *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice* have contributed to nursing’s growing capacity to promote such beneficial changes.

It is our hope that readers will step boldly into shaping the future of health care by becoming more engaged in ethical practice, and by becoming more confident in their leadership roles in health care. We believe that the content of our text can contribute to the knowledge needed for nurses to make ethical and political choices knowingly and wisely.

As a profession, nursing has achieved a great deal in regard to nursing ethics and promoting ethical practice. Yet, a great deal more needs to be done. Nurses must continue to demonstrate moral imagination and moral courage in the face of challenges that confront them at all levels of the health care system. Further, nurses are well positioned to take up the challenge of shaping the future health care system. We are confident that the ethical scholarship, practice, and political action of nurses will promote a future where health becomes an achievable goal for all people on our planet.
Endnotes

1 For example, we include a unique chapter (Chapter 5) where Indigenous nurses provide their perspectives in video format, and discuss the values and perspectives of Indigenous Peoples.

2 Moral distress is the anger, frustration, guilt, and powerlessness that HCPs experience when they believe that they are unable to uphold their values and their practice standards.

3 See Chapter 7 for examples of joint professional leadership.

References


From Ann Gallagher’s Foreword to this book:

“The abundance of scholarly riches in this book is made possible by the experience, expertise, and wisdom of three nurse ethicists with exemplary international reputations. Their scholarship, over many years, illuminates many pressing issues relating to bioethics, health care, and nursing. We can be grateful for their decision making, which resulted in the inclusion of 32 additional expert authors with diverse, wide-ranging, and enriching perspectives.”

“The breadth and depth of ethical issues explored, the frameworks discussed, and the extended range of topics included, make this third edition, now in an open access, digital format, an invaluable resource for nurse leaders, practitioners, educators, and researchers.”