



CHAPTER 15

Care of Older Adults: The Crises, the Challenges, and the Clarion Calls for Change

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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.² 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.
3. Self-care: people making choices and acting in the interest of their own health.

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).³ 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.⁴

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 1601,⁵ 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.⁶ 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).

REFLECTIVE QUESTIONS

1. *As a nurse leader in this scenario, what would have been your course of action to address this serious challenge to quality of care? Think about issues related to policy, communication, education, and engagement of families.*
2. *Who could you have contacted for further support?*
3. *In this scenario, where would your priorities lie and what would be the related ethical challenges?*

ETHICS IN PRACTICE 15-3

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).⁷ 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).⁸ 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.

ETHICS IN PRACTICE 15-4*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?*

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.

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

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.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

- 1 *Chronic Diseases: A Profile of Canadian Seniors*: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/aging-chronic-diseases-profile-canadian-seniors-report.html>
- 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/racism (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).
- 9 Visit Standards Council of Canada at www.scc.ca/en/flagships/long-term-care, Health Standards Organization at <https://healthstandards.org/general-updates/csa-group-hso-release-new-national-long-term-care-standards-public-review/>, and Canadian Standards Association at www.csagroup.org

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