



## CHAPTER 13

# Home Health Care: Ethics, Politics, and Policy<sup>1</sup>

**Elizabeth Peter and Shan Mohammed**

*“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.<sup>H</sup> 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).<sup>3</sup> 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.<sup>4</sup> 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

### **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.<sup>5</sup> 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**

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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

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- 1 This chapter is adapted and revised from: Peter, E. (2013). Home health care: Ethics, politics, and policy. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice* (2nd ed., pp. 384–397). Pearson.
- 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.

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