

# Restoring trust: COVID-19 and the future of long-term care in Canada

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## Abstract

The Royal Society of Canada Task Force on COVID-19 was formed in April 2020 to provide evidence-informed perspectives on major societal challenges in response to and recovery from COVID-19. The Task Force established a series of working groups to rapidly develop policy briefings, with the objective of supporting policy makers with evidence to inform their decisions. This paper reports the findings of the COVID-19 Long-Term Care (LTC) working group addressing a preferred future for LTC in Canada, with a specific focus on COVID-19 and the LTC workforce. First, the report addresses the research context and policy environment in Canada's LTC sector before COVID-19 and then summarizes the existing knowledge base for integrated solutions to challenges that exist in the LTC sector. Second, the report outlines vulnerabilities exposed because of COVID-19, including deficiencies in the LTC sector that contributed to the magnitude of the COVID-19 crisis. This section focuses especially on the characteristics of older adults living in nursing homes, their caregivers, and the physical environment of nursing homes as important contributors to the COVID-19 crisis. Finally, the report articulates principles for action and nine recommendations for action to help solve the workforce crisis in nursing homes.

**Key words:** long-term care, nursing homes, COVID-19, pandemic, quality of care, quality of life, end of life, LTC transformation, data quality, accountability

## Introduction

*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 (Humphrey 1977).*

The poor conditions of care in nursing homes have, with increasing frequency, been given prominence over the last 50 years in more than 100 published reports ([Table S1](#)). Those reports come from all high-income countries, but Canada has far more than its share. A quick search of the media for just the past 10 years yields over 150 reports in Canada alone ([Table S2](#)) describing unacceptable

and sometimes scandalous conditions experienced by our older adults in nursing homes. They all report similar findings, they all reflect our underlying outrage, they all make recommendations, they are all read, one or two actions are taken and then they all sit on a shelf. Nothing changes. Not really, not fundamentally. Of course great strides have been taken since the mid 20th century—newer nursing homes are organized with opportunities to better support quality of care and quality of life, dementia care programs are more regularly embedded in nursing homes, and encouraging examples of promising practices exist ([Armstrong and Baines 2018, 2019](#)). But still, concerns about quality of care and safety persist, tragic events continue, inequities deepen, root issues are not challenged, older adults suffer needlessly, and many Canadians are truly frightened at the prospect that they themselves may need to be admitted to a nursing home ([2nd Canadian Division and Joint Task Force \(East\) 2020](#); [4th Canadian Division Joint Task Force \(Central\) 2020](#); [Brewster and Kapelos 2020](#); [DiManno 2020](#); [Holroyd-Leduc and Laupacis 2020](#); [Kirkup 2020](#); [Lapierre 2020](#); [Perron and Marquis 2020](#)).

Each report and each event that motivated it are treated as isolated and unique. They are not. The persistent string of events that motivate the various reports and media coverage have their root causes in a long-fractured sector. The causes are multiple and complex, but their core is systemic and deeply institutionalized implicit attitudes about age and gender—running deeply and barely hidden. The state of nursing homes *is* solvable, but the solutions require choices.

COVID-19 did not, as we are hearing repeatedly, break this sector. It is simply another event. This time an event with high rates of fatalities in nursing homes globally. Nowhere are those excess death rates in nursing homes higher than in Canada ([Hsu et al. 2020](#)). 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 failed them. We broke the covenant. We have a duty, a responsibility and the ability to fix this—not just to fix the current communicable disease crisis, but to fix the sector that helped that crisis wreak such avoidable and tragic havoc. We can restore trust.

## How did LTC emerge and how it is governed in Canada?

Canada uses two encompassing terms for the full continuum of care outside acute care (hospitals)—long-term care (LTC) and continuing care. We focus here on 24-h residential LTC (often called nursing homes in Canada) as defined by Health Canada ([Government of Canada 2004](#)):

In general, long-term care facilities provide living accommodation for people who require on-site delivery of 24 hour, 7 days a week supervised care, including professional health services, personal care and services such as meals, laundry and housekeeping.

Most residential LTC for older adults in Canada has its roots in the Elizabethan Poor Law of 1601. In Quebec its roots are primarily in Christian religious orders. Canada's LTC sector first unfolded as poorhouses, county homes, parishes, poor farms and almshouses. These facilities housed people who were unable to care for themselves, including older adults, people with mental illnesses and people living in poverty. Depending on jurisdiction, some facilities were associated with charities and religious orders. Over time, people in different groups were separated into different facilities. Facilities housing only older adults were introduced gradually during the early part of the 20th century. Some of those early facilities were in use well into the 1950s in parts of Canada.

Provincial and territorial jurisdiction over LTC stems from interpretation of the Constitution Act of 1867. From 1977 to 1996 the federal government provided cost-shared funding for beds for the elderly and on a per capita basis for LTC, through its Canada Assistance Plan and Extended Health Care Services program. However, LTC remains outside universally insured health services protected by the Canada Health Act ([MacDonald 2015](#)). Health Canada notes that:

Long-term facilities-based care is not publicly insured under the Canada Health Act. It is governed by provincial and territorial legislation. Across the country, jurisdictions offer a different range of services and cost coverage. Consequently, there is little consistency across Canada in: what facilities are called (e.g., nursing home, personal care facility, residential continuing care facility, etc.), the level or type of care offered, how it is measured, how facilities are governed, or who owns them ([Government of Canada 2004](#)).

We summarize differences in LTC across provinces in [Table S3](#).

## Hope: Research offers promising practices in the LTC sector

Much of what follows in this report is sobering, but we must face the reality of what we have let happen in the care of our most vulnerable older adults. We must also learn from it, so that we do not continue to reach short-sighted and siloed solutions that just patch over the issues. Here we outline some of the promising practices in the LTC sector that exist internationally and across Canada.

A body of research (conducted by Working Group members and others) tackles multiple challenges and solutions in improving nursing homes:

- **Re-imagining Long Term Residential Care**—A research program led out of York University (Toronto) examines and evaluates approaches to care, work organization, accountability, and financing and ownership ([Armstrong 2020](#); [Armstrong and Armstrong 2020](#)). They also address unpaid work, invisible women and healthy aging in nursing homes.
- **Family/friend caregivers of older people needing assistance and formal caregivers and human resource issues in LTC and home care** ([Mount Saint Vincent University 2020a](#)). This research group out of Mount Saint Vincent University also studies end-of-life care in nursing homes, dementia care, rural aging and the physical nursing home environment ([Mount Saint Vincent University 2020b](#)).
- **Translating Research in Elder Care**, a longitudinal program of applied research in residential LTC at the University of Alberta ([TREC 2020](#)). This team studies quality of care, quality of life and quality of work life in nursing homes. They develop and evaluate strategies and interventions to improve quality in all these domains.

A number of the Working Group members have chaired panels investigating various aspects of quality in nursing homes ([Donner et al. 2012, 2015](#); [Bourbonnais and Ducharme 2015](#); [Keefe et al. 2018](#); [Bourbonnais et al. 2020](#)) or the roles of families ([Ducharme 2014](#); [Ducharme et al. 2015](#)), or have been active members of teams generating reports and recommendations ([MacDonald et al. 2019](#); [National Institute on Ageing 2019](#); [Research Institute for Aging 2019](#)). Their policy, data and legal expertise also informs this document. Other Working Group members have conducted research on family caregivers of persons with dementia ([Ducharme et al. 2015, 2016](#)), civil liberties, future financing of LTC ([MacDonald et al. 2019](#)), evidence-based care of older adults, personal support worker education, care worker communication ([McGilton et al. 2011](#)), the relationship between staffing and care quality ([Boscart et al. 2018](#)), care models for residential care settings ([Keller et al. 2017](#); [McGilton et al. 2018](#)), and impacts on the vulnerable during COVID-19 ([Armstrong et al. 2020](#); [Flood et al. 2020](#)).

Together, and in addition to an enormous international body of research on nursing homes, we have an abundance of promising solutions. There is no one solution. We can look for guidance to models used by other countries in Scandinavia and Europe, such as Dementia Villages and Green Farms. In our own country, excellent nursing homes have been studied and will continue to need to be studied. Some nursing homes in Canada in some locations prepared for and avoided COVID-19 infections

and deaths of residents to date, or have managed outbreaks well ([Mazur 2020](#)). For example, in Kingston, Ontario, long-term care homes have seen few COVID-19 cases. In Edmonton, Alberta, one family-run nursing home remains COVID-19 free. We need to understand how they were able to achieve this and why others did not. For example, what was the role of regulation and inspection in better or worse outcomes?

The first challenge is not that we lack evidence. We have a great deal of evidence that would contribute to major improvements, but this evidence has not been acted on.

Second, researchers alone cannot transform the LTC sector—our role is to bring high-quality evidence. Evidence, even when transformed into useable formats, still requires assessing and balancing benefit with issues of context, scale and cost. We have decades of evidence that languishes on shelves for many reasons, but at root the problem is a lack of political will to hear hard messages. One prime example is evidence on the right amount and type of staffing. This is, without any doubt whatsoever, one of the most critical components of quality in nursing homes.

Third, we must rigorously and comparatively evaluate reforms as they occur across Canada to improve LTC. This requires good data, something we are embarrassingly short of in the LTC sector.

Fourth, change in the LTC sector requires strong decisive leadership that is willing to move past incrementalism and tinkering at the margins to true transformative change. Leadership must also be willing to devote the resources needed to achieve this. We will need the ability and courage to not only implement promising practices, but also to cease practices that are not useful or effective.

Finally, and perhaps most importantly—if we are going to fix the LTC sector—Canadians and our governments will have to decide if it matters enough to us to do the hard work. This is a choice. We have a tremendous basis for hope that we can make this sector better for vulnerable older adults in nursing homes, but we will have to consciously and deliberately decide as a country to act on that hope.

## The two current components of the COVID-19 crisis in LTC

The current pandemic challenge in the LTC sector has two major components. First, this is a crisis of excess levels of mortality in nursing homes. These far exceed the mortality rates of seasonal influenza in nursing homes (0.1% vs. 3%–4%) ([World Health Organization 2020a, 2020b](#)). Numbers are changing rapidly, but to date Canada has the highest reported proportion of COVID-19 deaths internationally for nursing home residents. Canada reports that 81% of total COVID-19 deaths are of nursing home residents ([CIHI 2020a](#)). Other comparable countries report 27% (England and Wales) ([Comas-Herrera et al. 2020b](#)), 28% (Australia) ([CIHI 2020a](#)), 31% (US) ([CIHI 2020a](#)), 34% (Denmark) ([Comas-Herrera et al. 2020b](#)), 34% (Germany) ([CIHI 2020a](#)), 47% (Scotland) ([National Records of Scotland 2020](#)), 49% (Sweden) ([Comas-Herrera et al. 2020b](#)), and 66% (Spain) ([CIHI 2020a](#)). Globally the fatality rate for people who have COVID-19 is estimated at 3.4% ([World Health Organization 2020b](#)), but that rate varies strikingly from country to country—from as low as 0.1% (Qatar) to as high as 26.3% (Yemen) ([Johns Hopkins University Coronavirus Resource Center 2020](#)). In Canada the fatality rate is estimated at 8.2% ([Johns Hopkins University Coronavirus Resource Center 2020](#)) but the Canadian fatality rate of nursing home residents is estimated at 25% (range 11%–35%) ([Hsu et al. 2020](#)). The global fatality rate for all persons over age 85, regardless of location, is 10%–27% ([Centers for Disease Control and Prevention 2020](#)).

Second, and at least as disturbing, COVID-19 in nursing homes is a humane crisis. It is a crisis of how these older adults died and how they are still dying. In the most extreme cases seen in Europe, the US, and Canada, harsh media images remain with us—older adults abandoned, left alone to die in their

own excrement, without food or water, utterly alone (2nd Canadian Division and Joint Task Force (East) 2020; 4th Canadian Division Joint Task Force (Central) 2020; Brewster and Kapelos 2020; CBC News 2020a, 2020b; D'Amours 2020; DiManno 2020; Feinstein 2020; Hager 2020; Kirkup 2020; Lapierre 2020; Lee 2020; Perron and Marquis 2020). These images galvanized the world. Emergency measures have been instituted and the worst of this devastating crisis in a limited number of nursing homes has lessened, but older adults in nursing homes remain at extremely high risk—they are still dying and dying alone at high rates. Exacerbating the humane crisis is that 87% of nursing home residents have cognitive impairment (National Institute on Ageing 2019), 25% have a severe cognitive impairment (Hoben et al. 2019a), and two thirds have a stated diagnosis of dementia (Estabrooks et al. 2013; CIHI 2020c). They are anxious and afraid, unable to make sense of the people around them dressed in protective equipment, faces covered and voices muffled. These residents do best when things are familiar, but these are unfamiliar times in which to live and to die.

## Deep, long-standing causes of the COVID-19 crisis in the LTC sector

Canada's response to COVID-19 has exposed long-standing, wide-spread and pervasive deficiencies in the LTC sector. Deep operational cracks compromise a pandemic response. They also sabotage ongoing quality of care, quality of life and a good death, quality of work life for staff, and health and safety of residents, caregivers, family and staff. Deficiencies are underpinned by implicit negative attitudes on the value and need for expertise in LTC. While the following problems occur to potentially differing degrees in all jurisdictions, they are recognized as common across jurisdictions.

1. **Canada has failed to confront present and future financing of LTC.** This requires first identifying a national perspective on what older Canadians who need to live in a nursing home should be able to expect. Financing a sturdy LTC sector also connects intimately with all other components of continuing care, including community programming, home care, assisted living and retirement homes. When those interlocking components are stronger, needs for nursing homes will be lower. However, the need for nursing homes will not and should not go away. The key for older Canadians is the right care, in the right place, at the right time.
2. **Canada has failed to optimize integration across community, continuing care and acute care sectors.** These settings largely function independently and ignore the important and frequent transitions that happen across settings. Further, what happens in one of these settings, such as an outbreak of communicable disease, can and does affect all other sectors. Integration will require, among other things, robust linked data and a whole-system governance approach. If a whole-system approach had been in place, then hospitals would not have discharged people who tested positive for COVID-19 back to nursing homes without proper infection control.
3. **Canada lacks data for managing the LTC sector.** This lack is pervasive and deep. If Canada cannot measure the vital aspects of this sector, we cannot effectively manage it. Managing a complex sector such as LTC embedded in the larger continuing care sector—without data—is like managing with a Ouija board. However, standardized (or any) data collection, analysis and use remain minimal across Canada.

We have no shortage of data sources to cite. But this does not mean that Canada has sufficient data to manage a complex LTC sector. Many sources cited here are from other countries. Many studies cited are cross-sectional and cannot be used to determine causes. Studies are incredibly inconsistent in methods used and in the settings and individuals included. Few studies are longitudinal, and many are small “one-off” studies that we cannot confidently extrapolate to Canada's large, complex and heterogeneous LTC sector. It has been 25 years since the only available good quality, substantive multi-country comparison was carried out that included Canada (Van Nostrand et al. 1995). It focused on basic descriptions of services, residents, finding, regulations and staffing, and was somewhat biased to one province.



Canada requires data on its own nursing homes, on the residents, on the staff working in them and on the LTC sector broadly:

- Robust administrative data on aspects such as finances, payroll (staffing levels, actual hours worked by category of worker, staff mixes and costs), staff events (absences for illness or other reasons, turnover, retention, injury rates and costs) and resident dispositions (transfers to and from acute care, deaths in home vs in acute care, etc.). For COVID-19, such data must include availability of personal protective equipment (PPE), diagnostic supplies and testing, and medication stocks matched to master lists of residents where this is relevant.
  - Routinely collected and comparable data on *care quality* and outcomes of care. Currently not all provinces use the international standard of the interRAI suite of measurement tools for nursing homes ([interRAI 2020](#)).
  - Routinely collected data on quality of work life for all levels of the nursing home workforce using validated measurements. Examples of key data are job satisfaction, intention to leave, health status, burnout, work engagement, empowerment, and measures of work processes (e.g., missed care, rushed care, working short-staffed).
  - Routinely collected data on resident quality of life using measurement tools validated with people who have moderate to severe levels of dementia.
  - Routinely collected data on experiences of unpaid caregivers: family and friends of nursing home residents.
  - Routinely collected data on volunteers and paid companions.
  - Publicly available, comprehensive, and relevant data for each nursing home.
4. **Canada is not using data to act.** Having good quality, comprehensive and verified data is only half the battle. To be of value, data must be fed back to provincial and territorial governments, the federal government, the managers of health regions, nursing home organizations (e.g., owners and managers of chains of nursing homes), and importantly, managers of individual nursing homes. It must be acted on and the results evaluated. This is a continuous cycle required for any learning health system seeking to improve. The data must be in useable forms, with expectations and accountabilities for sound management. Just feeding back large quantities of data to managers in the LTC sector is completely inadequate. The data must be accessible and understandable, we must implement supports to help managers act on data and evaluate the impact of those actions, and accountabilities must be clear and transparent.
  5. **Canada has failed to look at LTC accreditation and regulation in a whole systems way, with best practices underpinning regulation.** We have also failed to systematically and regularly revisit regulation, monitoring and enforcement as a whole systems process. Nursing home care is both heavily regulated and highly risk-averse. Conversely, it is still missing critical pieces of regulation such as workforce standards and quality of work conditions. These broad regulation factors (or lack thereof) negatively affect quality of life and end of life, and quality of care. When we as individuals see a primary health care provider or go to a hospital, we have standards of expectation for staff preparation and experience. We do not expect to avoid all risk through severe restrictions in our own lives or in our health care.
  6. **Levels of regulated staff in nursing homes have been systematically reduced**, including staff providing medical coverage, regulated nursing staff and all other regulated health professionals such as physical and recreational therapists ([CIHI 2017](#)). Work by therapists, for example, links directly with both quality of care and quality of life. Social and spiritual care are too often nearly non-existent. Most members of these professional groups are women.
  7. **The unregulated workforce that provides upwards of 90% of direct resident care in nursing homes has no voice** ([Hewko et al. 2015](#)). We do not count these care aides and personal support workers accurately in Canada, we do not regulate them, and we do not have consistent

educational standards or ongoing continuing education standards for them across Canada. Despite their daily contact with residents, they are rarely engaged in decision-making about resident care and rarely included in family conferences. More than 90% are women, up to 70% are over 40, about 60% speak English as a second language (Estabrooks et al. 2015b; Chamberlain et al. 2019b), and about half in urban centres are immigrants (Estabrooks et al. 2015b; Chamberlain et al. 2019b).

8. **We have failed to support resilience of a paid nursing home workforce that is more than 90% women.** More women than men undertake significant caregiving responsibilities outside of work for children and for aging parents. Lack of affordable and accessible childcare or respite care sharply reduce the capacity of these workers to respond to crisis situations in their LTC work. Under pandemic conditions, and in preparation for a possible second wave of COVID-19, this must be changed immediately for the paid LTC workforce.
9. **We have not developed or adequately supported managers and leaders in the LTC sector,** either with adequate, ongoing leadership and management training or with sufficient resources to manage their nursing homes effectively and optimally.
10. **We have not maintained adequate levels of properly oriented dietary, laundry and housekeeping staff,** and have not recognized their role in creating a quality nursing home environment.
11. **Canada has generally failed to acknowledge the profound inequities and inequalities** faced by many older Canadians, which are exacerbated in nursing homes. High among them is poverty, a particular problem when fees are attached to many services and products and treatments. Poverty is an independent risk factor for lower health-related quality of life (McIntosh et al. 2009; Ross et al. 2009; Dorman et al. 2013; Tjepkema et al. 2013). We also see inequity and inequality based on mental illness, substance abuse and addiction, homelessness, absence of family or friends, intellectual and physical disability, visible minority status, Indigenous status and LGBTQ2S+<sup>1</sup> identity.
12. **Older Canadians with dementia living in nursing homes.** They are no longer part of Canada's economic engine. They no longer vote. They are rendered voiceless by advanced age, debilitating diseases and our inadequate care and attention. Two thirds of them are women, and two thirds of them are persons with dementia. Their voice must be restored.
13. **Canada has systematically failed to deal with the consequences of population trends in aging, dementia prevalence and fewer family caregivers for older adults.** We have relied increasingly on family to provide unpaid care without appropriately supporting them. We do not acknowledge the economic value of that care, or the high physical and mental health consequences of that work, or the loss of family caregivers from Canada's broader workforce (OECD 2011a; CIHI 2020d). Two thirds to three quarters of unpaid caregivers are women (National Center on Caregiving at Family Caregiver Alliance 2003; Chitayat 2009; OECD 2011a; Williams et al. 2012; CIHI 2020d). Under pandemic conditions, they may be caring for older family members and simultaneously home schooling children, bearing the brunt of the burden caused by the pandemic. Some families can afford to employ private paid companions for older adults with dementia in nursing homes during normal times, but those employees may or may not be formally trained to fill gaps in care and companionship. This also requires that families enter into employer relationships that they may be ill equipped to manage.

## The challenges ahead in nursing homes

### Pre-pandemic characteristics of older adults living in nursing homes

We cannot build a better sector if we do not understand the people it is intended to serve. By 2036, up to 25% of Canadians will be 65 or older (Statistics Canada 2018), with the most rapid growth in people

<sup>1</sup>LGBTQ2S+: Lesbian, gay, bisexual, transgender, questioning, two spirit. + refers to other sexual identities including pansexual, asexual and omnisexual.

85+ (Statistics Canada 2017b). Our changing population structure will sharply increase the number of Canadians living with Alzheimer's disease and other age-related dementias. Today, 1 in 40 Canadians aged 65–74 and 1 in 3 over 85 have an age-related dementia (CIHI 2010; Alzheimer Society of Canada 2016; Feldman and Estabrooks 2017). Without dramatic preventive, curative or treatment breakthroughs, more and more of these people will rely heavily on supportive care services such as nursing homes, especially in advanced stages of dementia.

At any given time about 1.2% of older Canadians live in nursing homes or residences for older adults (Statistics Canada 2017a). About 225 000 older adults live in nursing homes (Statistics Canada 2012) and another 168 000 in other types of residences for older adults (Statistics Canada 2012). However, turnover in nursing homes is rapid. About 80% of residents either die in the nursing home or are discharged or transferred to hospital immediately before death (McGregor et al. 2007; Menec et al. 2009). Thus, over the span of each year, many more than 225 000 older Canadians live in nursing homes. While waiting times for older adults to enter nursing homes are beyond the scope of this report, we know that they are unacceptably long: 150 d from community and 100 d from acute care in Ontario, for example (Ontario Long Term Care Association 2019; Health Quality Ontario 2020).

The characteristics of older adults in nursing homes have changed dramatically over the last two decades. From 2011/2012 to 2018/2019, the proportion of residents living with moderate to severe cognitive impairment passed 60% in most provinces and reached 68% in Ontario. During the same period, the proportion of residents aged 85+ (the oldest old) increased from 49% to 54% (CIHI 2013, 2020c). Canadians are now entering nursing homes when they are older, more dependent and have more complex medical and social needs (Hirdes et al. 2011; Doupe et al. 2012; Estabrooks et al. 2013; Koller et al. 2014; Paque et al. 2018; Hoben et al. 2019a; Armitage and Nellums 2020; Aung et al. 2020; CIHI 2020c; National Academies of Sciences, Engineering, and Medicine 2020; Simard and Volicer 2020). Between 65% and 70% of nursing home residents are women (Hirdes et al. 2011; OECD 2011b; Estabrooks et al. 2013; Public Health Agency of Canada 2018; CIHI 2020c). They have multiple co-existing health conditions, such as dementia and chronic heart, lung, kidney and metabolic diseases including diabetes.

Residents in nursing homes also more and more reflect the tremendous heterogeneity of Canadian society, for example:

- **LGBTQ2S+ identity:** Increasing numbers of LGBTQ2S+ older adults require nursing home care. Roughly 3% of Canadians identify as LGBTQ2S+, but actual numbers are underreported and likely much higher (Statistics Canada 2015). Members of the LGBTQ2S+ community are largely invisible within LTC sector services, and reporting on that community is often inaccurate and unreliable (Brotman et al. 2003). LGBTQ2S+ older adults express numerous fears about going to a nursing home (Schwinn and Dinkel 2015).
- **Require a public guardian:** Older adults with reduced decision-making capacity and no family or friends may require a public guardian (Chamberlain et al. 2018). Prevalence of this group in nursing homes is around 4% in Alberta and can be extrapolated to roughly 9000 people nationally (Chamberlain et al. 2019a). They often have unmet personal and care needs and experience poor quality of life (Chamberlain et al. 2020). Many have experienced homelessness or lived with mental health issues and alcohol or substance use (Chamberlain et al. 2020).
- **Mental illness:** Many more older adults in nursing homes have a serious mental illness than older adults in the community. Reportedly 40% of older adults living in nursing homes in Ontario need psychiatric services (Perlman et al. 2019), but less than 5% receive that care. Depression, dementia and anxiety are the most common mental health problems in nursing homes (Seitz et al. 2010). Bipolar depression, major depressive disorder and schizophrenia also occur independent of dementia (Fornaro et al. 2020). A recent review reports that nearly 25% of nursing home residents in North America without dementia experience major depressive



disorders (Fornaro et al. 2020). In Canada, 27% have depression and approximately 23% have depression and dementia (Seitz et al. 2010; Hoben et al. 2019b).

- **Race:** Canada is multi-racial and that is reflected in our nursing homes, but data on race and ethnic group are not routinely collected (Scofield 2020). This is particularly problematic because COVID-19 has differentially affected racialized populations.

## Pre-pandemic characteristics of care for older adults living in nursing homes

The goals of care in nursing homes differ radically from goals in the acute care (hospital) sector. For nursing home residents, their goals of care centre on quality of life, quality of life as the end of life nears, and a good death. A good death is an eventual, anticipated and appropriate outcome. In the US in 2009, 1 in 4 deaths of people on Medicare occurred in nursing homes. (Teno et al. 2013). Despite this and although palliative care in nursing homes is rapidly evolving (Hunt et al. 2020), palliative services are often unavailable (Dingfield et al. 2020). We do know that older adults in Canada face significant gaps in accessing palliative services (CIHI 2020b), but we do not have evidence on the quality of palliative care in nursing homes across Canada or to what extent “palliative approaches” are implemented (Sawatsky et al. 2017). We do know that structural inequity has a profound impact on access to palliative care generally (Stajduhar 2020).

Residents of nursing homes experience unacceptable rates of highly burdensome symptoms and high rates of potentially inappropriate care at the end of life in Canada (Estabrooks et al. 2015a; Hoben et al. 2016) and internationally (Mitchell et al. 2009, 2016; Hendriks et al. 2015). Burdensome symptoms are highly distressing, largely preventable or treatable, and cause unnecessary suffering. Common burdensome symptoms for nursing home residents are pain (26%–86%) (Bernabei et al. 1998; Won et al. 1999, 2004; Reynolds et al. 2002; Hanson et al. 2008; Duncan et al. 2009; Hunnicutt et al. 2017; Ersek et al. 2020), eating problems (47%–70%) (Reynolds et al. 2002; Hanson et al. 2008, 2013; Lindroos et al. 2019), shortness of breath (10%–75%) (Hall et al. 2002; Reynolds et al. 2002; Hanson et al. 2008; Duncan et al. 2009; Drageset et al. 2014; Hendriks et al. 2015), and delirium (29%–46%) (Hall et al. 2002; Duncan et al. 2009; Cheung et al. 2018).

On average, nursing home residents experience more than one transfer to hospital in their last days of life (Li et al. 2013; Temkin-Greener et al. 2013; Mitchell 2015; McCarthy et al. 2020). Of those transfers, 75% could have been avoided because appropriate treatment was available in the nursing home or because transfer to hospital was inconsistent with resident and family preferences (Givens et al. 2012; Mitchell 2015). Common (but usually inappropriate) care at end of life in nursing homes includes administering antipsychotic medication without a diagnosis of psychosis (Schneider et al. 2006; Banerjee 2009; Declercq et al. 2013; Juola et al. 2016; Gurwitz et al. 2017), inappropriate medication management for depression (Burns and Winblad 2006; Choi et al. 2008), use of physical restraints (Engberg et al. 2008; Castle and Engberg 2009; Köpke et al. 2012; Foebel et al. 2016; Abraham et al. 2019), multiple simultaneous medications prescribed (Tamura et al. 2012; Jokanovic et al. 2015; Kröger et al. 2015; Martín-Pérez et al. 2019), indwelling urinary catheters (Flaherty 2004; Getliffe 2008; Gurwitz et al. 2016), and aggressive treatments such as renal dialysis (Muthalagappan et al. 2013; Tamura et al. 2017) or non-pain-related intravenous therapy such as antibiotics (Mitchell et al. 2004; Volicer 2004; Thompson et al. 2020).

Nursing home care in Canada is not structured or staffed to maintain or improve the functional abilities of residents. For example, residents often lose functional mobility rapidly (Slaughter et al. 2011). Up to 70% of nursing home residents use wheelchairs (Gavin-Dreschnack et al. 2005; Wick and Zanni 2007; Hirdes et al. 2011; Giesbrecht et al. 2017), putting them at high risk for injury from falls, incontinence, pressure injuries and pneumonia (Slaughter et al. 2015).

### The special case of dementia

Life expectancy continues to rise in Canada, along with chronic diseases. On average, Canadian women can expect to live 84 years and men 79.9 years ([Statistics Canada 2019](#)). Critically for the LTC sector, dementia has increased dramatically. Globally, 75 million people will have a dementia by 2030 and 131.5 million by 2050 ([Alzheimer's Disease International 2015](#)). Today, one in 40 Canadians aged 65–74 years old and one in three over 85 years old have an age-related dementia ([CIHI 2010](#); [Alzheimer Society of Canada 2016](#); [Feldman and Estabrooks 2017](#)). By 2038 1.125 million Canadians, or almost 3% of the entire population, are projected to have an age-related dementia ([CIHI 2010](#)). Rates of dementia will continue to climb because age is the major risk factor.

Dementia is itself life-limiting. Dementia is an umbrella term for a set of degenerative brain disorders. It results in decreasing cognitive and functional abilities, starting with higher brain functions for planning, focus and memory. Eventually even low brain activities such as bladder and bowel control, recognition, moving and swallowing do not function. Dementia is ultimately fatal if something else does not cause death first, such as pneumonia ([Kua et al. 2014](#); [Haaksma et al. 2018](#)). People with dementia experience progressive decline. Even assuming optimization of all community care, home care and alternative supported living, eventually the care demands of dementia normally exceed the coping capacity of family and community. Unsurprisingly then, dementia is the major driver of admission to nursing homes. More than two-thirds of older adults with dementia will require nursing home care ([Toot et al. 2017](#); [U.S. Department of Health and Human Services 2017](#)). Dementia can be an untenable challenge during crises such as COVID-19—and some countries have discussed rationing of resources for people with dementia, raising complex questions of discrimination and vulnerability ([Cipriani and Fiorino 2020](#)). We are also learning that older adults with dementia have a different disease course and symptoms for COVID-19 and have higher mortality rates than those without dementia ([Bianchetti et al. 2020](#)).

Dementia defines the complex health and social care that is required in nursing homes. Dementia care is demanding and specialized ([Kuske et al. 2007](#); [Rapaport et al. 2017](#); [Alzheimer Society of Canada 2020](#); [Wang et al. 2020](#)). It requires knowledgeable and skilled staff. It is patently false that anyone can provide health and social care for people with dementia.

### Pre-pandemic characteristics of the workforce in LTC

We cannot build a better LTC sector if we do not understand, value, train and appropriately compensate the people who deliver the essential services needed by the older adults living in nursing homes. In the past, many older adults lived in an “old age home.” People who required a higher level of medical care lived in facilities staffed by regulated nurses (registered nurses and licensed practical nurses), with some complementary care by nursing assistants or orderlies. As costs increased, staff configurations changed.

Today we see a decline in all regulated caregivers in most jurisdictions ([McGregor et al. 2010](#); [Seblega et al. 2010](#))—even as the medical and social needs of older adults in nursing homes have risen sharply. The dominant staffing model in nursing homes now is a few registered nurses and some licensed practical nurses. Most direct care of residents is carried out by unregulated staff variously called care aides, personal support workers, orderlies or nurse assistants. Small numbers of other regulated care providers are included in the mix: physiotherapists and physio aides, recreation therapists and aides, social workers, occupational therapists, and others. Evidence exists, and continues to grow, that staffing levels and staffing mix are linked to quality of care ([Bostick et al. 2006](#); [Castle 2008](#); [Hyer et al. 2011](#); [Spilsbury et al. 2011](#); [Backhaus et al. 2014](#)) and quality of work life ([Cummings et al. 2017](#)).

## The unregulated paid workforce

### *Personal support workers, care aides, orderlies, nurse assistants*

Workers in nursing homes care for frail, vulnerable older adults with increasingly complex medical and social needs. Those needs of residents have a significant impact on unregulated care aides, the predominant staff in nursing homes who provide upwards of 90% of direct care (Office of Inspector General 2002; Association of Canadian Community Colleges 2012; Baughman and Smith 2012; Daly and Szebehely 2012; Caspar 2014). Care aides have limited formal training and manage high workloads with frequent interruptions (Mallidou et al. 2013). They frequently experience responsive behaviours of dementia from residents, such as being yelled at and hit (Zeller et al. 2009; Estabrooks et al. 2015b; Hewko et al. 2015; Chamberlain et al. 2019b). They are at high risk for job dissatisfaction (Squires et al. 2015), burnout (Chamberlain et al. 2017) and poor mental and physical health (Hoben et al. 2017). In addition, care aides are themselves a vulnerable group, mostly older women from ethnic minorities (Chamberlain et al. 2019b).

Canada cannot currently plan for a workforce with sufficient numbers of well-trained staff to secure quality care in nursing homes. We do not even accurately count the numbers of unregulated workers providing care in Canadian nursing homes or in other LTC settings, such as retirement homes or private homes. It is impossible using data national data sources to tease out where the unregulated workers are actually working and in what numbers. No data are routinely collected nationally or provincially on the characteristics of the care aide workforce or on the quality of their work life or on standards in each province for their training.

By searching websites and tapping our professional networks in the LTC sector, we collected limited information on care aides nationally (Table S4). From published research, media reports and informal channels, we also know that, pre-pandemic:

- Care aides receive the lowest wages in the health care sector (\$12–\$24 per hour) (CBC News 2020c; Henderson 2020; Government of Alberta n.d.).
- Care aides receive variable and minimal formal education.
- Many care aides cannot get full-time or regular part-time work with benefits, because some employers rely on casual staff (McGilton et al. 2020; Yinfei et al. 2020).
- In some provinces, such as Ontario, many care aides are hired out on demand to nursing homes through agencies. Care aides with these agencies are not well paid, although nursing homes pay a premium for them. Agency staff may not be well oriented to LTC, making team work more difficult and increasing the work of already stretched staff.
- No groups of care aides are regulated or licensed in Canada. Few are registered (Estabrooks et al. 2015b; Kelly and Bourgeault 2015; Chamberlain et al. 2019b).
- All care aides work at the bottom of a rigid hierarchy. They are rarely engaged in decision-making about care for residents and rarely included in family conferences or in decisions about how a nursing home is organized or governed (Song et al. 2020b).
- Pre-pandemic, a nursing home resident received only 2.2–2.3 h of direct (worked) care from care aides in each 24-h period (Estabrooks et al. 2015b; Cummings et al. 2017).

Largely from an ongoing longitudinal study in western Canada we know that, pre-pandemic, frontline care aides:

- are mainly middle-aged or older women (66%–71%) (Estabrooks et al. 2015b)
- are often newcomers or immigrants (60% of care aides working in urban areas), with English as their second language (Chamberlain et al. 2019b)

- are often not required to complete any continuing education and are often not offered it (Estabrooks et al. 2015b)
- often work in more than one job (25%–30%) and in health care settings other than nursing homes (e.g., hospitals; 15%) (Estabrooks et al. 2015b; Hewko et al. 2015; Chamberlain et al. 2019b; Song et al. 2020a; Van Houtven et al. 2020; Yinfei et al. 2020)
- often work short-staffed (Song et al. 2020b)
- have insufficient time to complete necessary care tasks and must rush essential care (up to 65% of care aides per shift) (Song et al. 2020a)
- are at worryingly high risk for burnout and physical injury (Estabrooks et al. 2015b; Hewko et al. 2015; Chamberlain et al. 2017, 2019b)
- report feeling that their work is important and has meaning, despite high levels of work-related stress (Estabrooks et al. 2015b; Chamberlain et al. 2019b; Song et al. 2020b)

The impact of COVID-19 on psychological health and safety of direct care workers in nursing homes is being added to already worrisome pre-existing trends (Braedley et al. 2018). Studies from the 2003 SARS epidemic (Styr et al. 2008) and recent studies documenting effects of the COVID-19 pandemic on point-of-care workers in China (Lai et al. 2020b) point to severe long-term traumatic impacts on mental health of point-of-care staff. Care aides are already under severe psychological stress and are predicted to develop symptoms of acute stress disorder, depression, alcohol abuse, anxiety, insomnia and posttraumatic stress disorder (PTSD) even years after the COVID-19 pandemic (Brooks et al. 2020).

#### *Unregulated indirect care workers*

Additional large groups of unregulated workers in nursing homes are housekeeping, laundry and food services staff. They contribute importantly to infection control, to the sense of each nursing home as home for residents, and to quality of life (Müller et al. 2018). However, many such services are contracted out and those staff are less integrated into nursing homes. Despite their essential work, we have little data on them and few studies include them. A notable exception is work out of York University (Armstrong 2020; Armstrong et al. 2020). Although these workers are rarely considered when nursing home reform and redesign are discussed, they are key to a high-quality and safe nursing home.

#### *The regulated paid workforce*

Medical coverage in nursing homes varies significantly across provinces, from a designated roster of family physicians who care for residents at one or more nursing homes to an individual resident's family physician (Ågotnes et al. 2019). Some regions use combinations of these or offer almost no care on site ("medical care by fax"). A few provinces and regions offer medical coverage by nurse practitioners, either primarily or in collaboration with general and specialist medical services. Access to mental health services varies widely and is usually by consultation only when it is available (Grabowski et al. 2010). Mental health and palliative services are generally insufficient to meet demand (CIHI 2018). We still know little about availability of palliative services for residents who died in nursing homes under COVID-19 conditions.

Nursing homes also require a diverse cadre of regulated nursing and other health professionals. Most numerous are nurses—registered nurses, licensed practical nurses and registered psychiatric nurses (and in some nursing homes in some provinces, nurse practitioners). Over the past two decades, ratios of regulated nurses to care aides have steadily declined (Statistics Canada 2006; McGregor et al. 2010). At the same time, regulated nursing staff must give more time to required documentation

(“paperwork”)—time that is taken from direct care and supervision. Numbers of registered nurses have also decreased in favour of licensed practical nurses as a cost saving measure (McGregor et al. 2010). These changes reflect widening inability or reluctance to meet the increasingly complex needs of nursing home residents by matching those needs to appropriate nursing skills (McGilton et al. 2020).

Nursing homes often lack access to an array of specialized services accessible to all residents. Residents often need support from physical, occupational, speech and recreational therapists and technicians. Skills of those workers affect both care quality and quality of life by prolonging mobility, optimizing assistive devices, assisting with swallowing difficulties (often encountered by people with later-stage dementia), and programming meaningful recreational and social options. Social workers and pastoral care are important in assisting both residents and families. However, as cost containment becomes more pressing, all regulated services have dwindled despite a resident population with higher needs than ever before (McGregor et al. 2010; Hsu et al. 2016).

Many nursing home residents need access to uninsured services such as vision care, dental care, hearing care, podiatry, assessment for hip protectors, and special mobility devices or wheelchairs. Few mobile services come to nursing homes, so residents and caregivers (paid or unpaid) must travel to the service. Not all service providers even can or will offer services to nursing home residents with impaired mobility or dementia.

Sensory loss is a major impairment in dementia, making lack of vision and hearing services a serious concern. Lack of dental care is a major problem for health, quality of care and quality of life (Hoben et al. 2020; Yoon et al. 2020). Dental needs are increasing dramatically as Canadians age with their own teeth and with complex dental work (bridges, crowns, implants) that require specialized care—care that is not available in nursing homes.

### Workforce staffing and staffing mix for quality of care and quality of life

Most studies on appropriate staffing mix in acute care and nursing homes have been in the US, with some in Europe and almost none in Canada. Most studies in acute care are highly focused on effects of daily hours (Aiken and Sloane 2020) of nursing care on one outcome, such as mortality (Estabrooks et al. 2005; McHugh et al. 2016). Recent papers point out wide differences in regulated staffing hours (Geng et al. 2019). Reviews of staffing studies, most in the US (Spilsbury et al. 2011; Castle 2012; Backhaus et al. 2014; Dellefield et al. 2015; Easton et al. 2016), all identify major issues with how studies were conducted and lack of comparability across studies. However, a body of evidence has emerged despite the inherent challenges of cross-sectional studies and other methodological challenges. In 2001, the Centres for Medicare & Medicaid Services in the US issued a major report to Congress on nursing home staffing (Centers for Medicare & Medicaid Services 2001). Since then multiple reports have increased pressure and guidance, despite the challenges, to bring standards to bear on US nursing homes. US health care is organized differently and data and findings are not directly translatable to Canada, but they illustrate trends that likely are significantly similar between the two countries. If staffing is inadequate, quality plummets.

A useful process proposed to establish adequate and appropriate staffing by all groups of nursing personnel is to: (a) determine the collective resident care needs, (b) determine the actual nurse staffing levels, (c) identify appropriate nurse staffing levels to meet resident’s care needs, (d) examine evidence on the adequacy of staffing, and (e) identify gaps between the actual and appropriate staffing levels (Harrington et al. 2020). Harrington, a recognized US leader and expert in nursing home staffing, also advises that the minimum total nursing hours to ensure care quality is about 4.1 h per resident per 24 h (Harrington et al. 2016). This does not include physician care or the allied services required for



good care quality (medical, physical, occupational, recreational, speech and language therapy, social work, pastoral care, support from laundry, housekeeping and dietary). This estimated requirement of 4.1 h of nursing care in 24 h is significantly higher than nursing hours in Canada—BC has the highest *recommended* funded hours per resident day at 3.36 h, higher than the Canadian average of 3.30 (BC Care Providers Association 2019; Office of the Seniors Advocate 2020).

Importantly, adequate staffing is a necessary but insufficient condition for quality (Kane 2004). A nursing home is a complex adaptive system with many moving parts and multiple elements that contribute to quality of care and quality of life for residents (Anderson et al. 2003; Forbes-Thompson et al. 2007). We must not focus attention exclusively on staffing and think this will solve the challenge of quality. Other essential dimensions of quality are person-centered and relational care, strong leadership and management, working conditions and the care unit environment, the built environment, and resident and family/friend experiences. And these are just some of the essential elements required for quality. To improve quality of care, we need data that are routinely collected in multiple areas, in multiple forms—and we must put in place mechanisms and supports for these data to be acted upon and those actions evaluated. Quality data and action cycles are hallmarks of a learning health system (Lessard et al. 2017).

Canada lacks a comprehensive, data-based assessment of necessary staffing in nursing homes—minimum hours of care needed to give an acceptable level for quality of care and quality of life. Minimum hours of care must be based on each resident's needs, on how complex their social and medical needs are and on acute needs. Assessing necessary staffing in nursing homes must also thoughtfully consider the care team required to deliver quality care. This must include staffing and skill mixes and the widest possible definition of a care team. A staffing assessment for nursing homes must also consider the needs (and solutions for those needs) of a predominately female workforce, such as childcare and care for aging parents. Finally, it must consider cost, benefit and sustained implementation.

No comprehensive empirical work has ever been done in Canada to determine minimal, adequate, appropriate, or optimal staffing needed to ensure good quality social care (quality of life) and health care (quality of care) for residents. It is long overdue.

### Care by unpaid family and friends

The LTC sector and nursing homes rely increasingly on unpaid care by family members and friends of residents. These are disproportionately women, especially for daily care. They provide many different care activities. However, our society gives little attention to respite for these caregivers or to the negative effects of their caregiving burdens.

Compounding this problem, by 2050 approximately 30% fewer close family members—spouses and adult children—will be available to give this unpaid care (Carrière et al. 2007). Family configurations are changing with declining fertility rates, smaller families and families dispersed across the country and internationally. More people will have no available family or friends. Relying on unpaid care by family and friends leaves the LTC sector especially vulnerable in crises such as COVID-19, when those unpaid caregivers suddenly become unavailable—or as in the first wave of COVID-19, are not permitted into the nursing home. As with aging of our population and rising levels of dementia, the dwindling numbers of unpaid family caregivers can be predicted with some certainty—when it occurs it will not be a surprise. Whether we will be ready is uncertain.

Volunteers are often proposed to meet gaps in care and social activities for nursing home residents. However, this is not a straight-forward solution. Are there enough trained volunteers regularly available? Do volunteers receive planning, orientation and support for equitable, safe and

consistent care? Are we using volunteers as a substitute for experienced and knowledgeable workers and is that appropriate? Care for residents in nursing homes is not care that just anybody can do. For example, having volunteers help residents with eating requires special training on problems with swallowing and risk of choking. Even in social activities, volunteers must be keenly aware of challenges in communicating with people living with dementia and associated disruptive behaviors.

## Pre-pandemic characteristics of social, living and working spaces in nursing homes

### Physical environment

The physical layout of nursing homes (~1800 in Canada) does not help to contain viruses or control infection, even in newer homes. Many nursing homes in Canada are old and were built between 1950 and 1990. Older buildings tend to be larger, with 200–400 residents. They resemble hospitals, with communal bathrooms, rooms for 2–4 residents, narrower hallways, large communal dining areas, small crowded nursing stations and medication areas, and limited areas for staff and families away from resident rooms. They may lack outdoor areas or adequate natural light and certainly lack modern technologies that improve care, such as appropriate flooring ([Lachance et al. 2017](#)). Physical distancing is nearly impossible without reducing the number of residents. Isolation or segregation of residents infected with COVID-19 is difficult within the design of these older buildings. Worryingly, we are seeing early reports of associations between facility size and age and COVID-19 status ([MacDonald et al. 2019](#); [Abrams et al. 2020](#)).

Nursing homes built in the last 20 years often accommodate only 80–120 residents. They are designed specifically to support the social needs of residents living with dementia, with smaller “neighborhoods” of residents, physical characteristics that make living less stressful and more enjoyable for people with dementia, wide hallways and doorways, individual large bathrooms, and smaller local communal dining areas. They often have spacious and safe outdoor spaces where people living with dementia can enjoy the outdoors without danger of wandering. At least three provinces have building standards for nursing home construction that include these features (NS, AB, ON). These standards can also make physical distancing and infection control less challenging.

### Plans, protocols, and resources for delivering care

When the COVID-19 outbreak occurred, nursing homes lacked capacity to handle the surge. They faced a major challenge in rethinking what care to deliver and how to deliver it. Quality of life and quality of care for residents became secondary in many instances. To have been fully prepared, nursing homes would have needed multiple plans and resources:

- infection prevention and control through PPE sourcing and training in its use and conservation
- strategies for clustering and isolating ill residents and those who tested positive
- infection surveillance strategies for staff
- appropriate policies on visitors, recognizing the risk of infection, but also recognizing how essential friends and family are to both residents’ quality of life and in providing care in understaffed facilities
- capacity to test and carry out contact tracing
- sufficient staff with relevant training to fill staff vacancies from illness and self-isolation, as well as volunteer vacancies
- effective on-site leadership and management

- ongoing, productive links to acute care hospitals
- training in end-of-life care and access to relevant medications and staff to administer them
- resources for end-of-life decisions
- wellness resources for staff
- adequate IT capacity and internet access to enable video communication with families and others

An additional complexity is that nursing homes are a social environment. Much work has been done to invite the community—families, volunteers, children, pets—into nursing homes. Many policies normally welcome this influx, rather than managing it—no set visiting hours, open door policies, free inflow of food and pets, and residents free to leave and return. Under COVID-19, nursing homes as a public social place clashed sharply with nursing homes as a safe space for residents to live and staff to work. Staff were charged with keeping the space safe. Clearly, having so many homes become hotspots for COVID-19 put an enormous strain on the willingness of residents, family and staff to comply with changes in policies in favour of safety. Communication has been a problem in many, although not all, nursing homes.

## The context that created the COVID-19 crisis in LTC

Several factors operated to create the high degree of vulnerability experienced by older adults in nursing homes:

1. **Pandemic preparedness favoured acute care (hospital) settings.** Nearly all effort was diverted to create surge capacity in hospitals and ICUs, leaving most nursing homes unprepared and (worse) in some jurisdictions admitting older adults from acute care.
2. **Residents in nursing homes have reduced immune system capacity as a result of aging.** This markedly reduces their ability to fight any infection.
3. **COVID-19 is novel.** Neither nursing home residents nor staff are vaccinated against it, unlike annual influenzas for which most residents and staff are vaccinated. Such vaccination offers herd immunity.
4. **COVID-19 is highly contagious and has a long incubation period when infected people have no symptoms.** Spread can be invisible. In the early weeks of the pandemic, before this was widely known, invisible asymptomatic spread was deadly. The virus spread into and back out of nursing homes as family, visitors and staff came and went unknowingly. Basic infection control practices and PPE that should have been in place were too often missing. A proportion of nursing home staff were working in more than one nursing home and other health care facilities, silently bringing the virus in and out of nursing homes in the early weeks.
5. **Many nursing homes in Canada are physically not designed for infection control practices** that are needed to avoid COVID-19 or to contain its spread. Nursing homes have many communal settings, including bathrooms, dining areas and rooms with multiple beds. Separation of COVID-19 positive residents was not recognized as critical in the early days, and many nursing homes are not physically designed to make this achievable. This is particularly challenging in care for people living with dementia who are also at risk of wandering and cannot remember to physically distance.
6. **Staff did not know or misunderstood how to prevent and control the spread of COVID-19 in the early days of the pandemic.** Infection control knowledge was inadequate among care staff. The ways that nursing homes were managed to control spread varied significantly between and within provinces.

7. **Nursing homes experienced shortages of PPE, problems, and lack of support in teaching how to use PPE properly, and lack of understanding that PPE was essential for nursing homes.** At times, PPE was pulled from nursing homes for the acute care sector (Butler 2020; Eaton 2020). Nursing home staff must be routinely in close contact with residents and must have PPE to care for residents adequately under COVID-19. Often PPE and education in its use did not include critical staff for infection control, such as housekeeping.
8. **Some hospitals discharged patients who tested positive for COVID-19 to nursing homes.** Some hospitals would not accept infected patients from LTC settings.
9. **Up to 30% of care aides and other staff worked at more than one job.** Because care aides are not in registries, these numbers were not known or considered. In the early stages of the pandemic this increased spread of COVID-19 infection.
10. **Many nursing homes lacked screening resources for symptoms, travel history, and contacts of both residents and staff.** Many also lacked testing, contact tracing and plans to respond effectively.
11. **Staff were not able to work, for many reasons.** Some were symptomatic and had to isolate at home. Some were sick or had a sick family member. Some had to care for children at home when schools closed. Some were afraid to work or in some instances left their posts. Fear and misinformation led to pressure on staff from families, landlords and unions to stay away from nursing homes with COVID-19 cases. The LTC sector works with a complex combination of barely enough full-time staff and mostly part-time staff. It fills the gaps with casual and agency staff, with few reserves to replace absent workers. Families, who often provide significant care, were not permitted to visit. The LTC sector could not meet unexpected pandemic pressures from reduced staffing and volunteers and the 24/7 needs of residents. Those pressures quickly became catastrophic.
12. **Troubling reports from Europe (Diamantis et al. 2020) and now Canada (2nd Canadian Division and Joint Task Force (East) 2020; 4th Canadian Division Joint Task Force (Central) 2020) indicate that many preventable deaths occurred in nursing homes under COVID-19.** Some deaths were from lack of timely care, water, food or basic hygiene, not from COVID-19 infection. This underscores the frail and highly vulnerable condition of older adults in nursing homes. It epitomizes our failure. Many are not mobile or cannot vocalize their needs. This was more than a communicable disease crisis.

## Principles to guide future action

While there is more to be learned about controlling COVID-19, the following principles should guide efforts to improve safety and quality of life for residents and staff of Canadian nursing homes. We must create a better future for older Canadians who need nursing home care and ensure their voices and wishes are honoured. At their heart these principles are about our shared values as Canadians.

1. Funding must be adequate and sustained, with the federal government supporting provincial and territorial governments to achieve high standards across Canada in LTC.
2. Quality of care in nursing homes is fundamental and intimately linked to quality of life.
3. Quality of life for the frail elderly is a non-negotiable objective.
4. Quality of end of life and a good death are similarly non-negotiable objectives.
5. Standards of care are essential and must be clearly articulated along with accountability.
6. Responsibility for policy, standards, and regulation must be clear. Desired outcomes must be articulated and evaluated, and accountability for those outcomes ensured.
7. Routine evaluation of performance must occur, including performance measures that are important to residents and families.

8. High-quality and comprehensive data (quantitative and qualitative) are required to manage the LTC sector and must be routinely collected, verified, analyzed, and reported for effective regulation, evaluation and monitoring.
9. Mechanisms for acting on data must be in place and be supported from point-of-care to policy levels.
10. Funding for nursing homes must be tied to ongoing evaluating and monitoring of indicators of quality of care, resident quality of life and quality of end of life, staff quality of worklife, and resident and family experiences. All information must be publicly accessible.
11. The federal government must take a major role and develop a mechanism for supporting provincial and territorial governments to achieve high standards in LTC across Canada. This could be achieved through a similar framework to the Canada Health Act, where core standards are articulated. Provincial and territorial governments who meet those standards receive the additional federal LTC transfer.
12. Working relationships must be collaborative among stakeholders—government, health authorities, nursing home owners and nursing homes themselves, with the vital input of the people who live, work in and visit nursing homes.
13. All citizens in all regions must have universal, affordable, and equitable access to 24/7 nursing home care, if they need it, without long wait lists.
14. There must be better integration across community, continuing care and acute care sectors. Transitions between LTC settings must be better managed, with a whole-systems approach to governance, regulation and incentive design.
15. Nursing home staffing must be consistent and adequate, with qualified staff in the right mix of skill and knowledge.
16. Nursing home physical environments and plans, protocols and resources for delivering care must meet complex medical, social and home-like needs of residents. They must also meet complex needs for space, safety and infection control and prevention. They must not sacrifice the ability of close family members (of origin or choice) to assist with care and be with dying residents.

## Recommendations to manage COVID-19 in Canada's LTC sector

Reform and redesign will take time. Multiple organizations globally have begun to outline the many specific and immediately practical things that need to be done to manage COVID-19 in LTC in the shorter term (Dosa et al. 2020; Hsu et al. 2020; Lai et al. 2020a; Ouslander 2020). In May 2020, Comas-Herrera et al. (2020a) outlined policy recommendations. Subsequently, members of this working group laid out their prescription in seven actions for preparing for the second wave of COVID-19 in nursing homes, reproduced here (Estabrooks et al. 2020).

“First, all (not just some) nursing homes, retirement homes and other assisted living places must each have an approved plan for responding to infectious outbreaks, including COVID-19. The plan must specify who is responsible for preventing and managing an outbreak and that person must be on site, with clear and measurable performance metrics. Residents and their families must be consulted in the development of the plan and there must be transparent reporting to the public.

Second, in-person inspection of all homes must occur regularly by the relevant public health unit (and not by an accreditation body) to ensure that plans are being operationalized and that residents and workers are safe. It should go without saying that such inspections cannot be by telephone and that



LTC facilities should not be warned ahead of the inspection, which is the practice in some provinces. Results of inspections must be made public and there must be consequences for non-compliance.

Third, provincial governments must manage procurement so that LTC settings are equipped for infection control. All workers or others who come into close contact with residents in LTC settings must be equipped with adequate PPE. These same people must have proper education in infection prevention and regular ongoing support and re-education in infection control and proper PPE use and conservation. Also, all nursing homes must adopt and have resources for a “test and trace” strategy for all residents and all workers.

Fourth, LTC workers must have full time work with equitable pay and benefits, including mental health supports for the PTSD many are experiencing due to COVID-19. Many personal support workers work for minimum wage, which is unacceptable normally, given the importance of this work and the expertise required. It is ridiculous in the face of COVID-19, given the personal risks for workers and their families. Similarly, workers providing essential food, cleaning and laundry services must receive equitable pay. When the military was deployed into LTC homes, in Quebec and Ontario they were paid “danger” pay on top of their relatively robust salaries.

Fifth, jurisdictions must continue the “one site work policy” both for the duration of the pandemic and going forward. Working in two or more settings contributed to COVID-19 spread both in and out of facilities and contributes to the spread of influenza at other times.

Sixth, all LTC homes must either have the capability of properly isolating an individual with COVID-19 or clustering positive residents in one area of the LTC home. If this is not feasible, the patient must be transferred to a hospital or other appropriate setting where isolation of positive cases is possible. No hospital should discharge any suspected or confirmed case of COVID-19 back to a nursing home until the person’s infection has resolved as evidenced by a negative test. Plans for managing COVID-19 must also include access to palliative care if needed, including appropriate medications and pain control.

Seventh, response plans for LTC homes must include measures so that technology and other means are fully employed to connect residents with family and friends and that at least one or two family members can safely visit (with PPE and proper infection control practices and training). Residents are closer to the end of their lives; many have dementia. Familiar voices, support and comfort are essential, and sometimes only a family member or friend can provide that. We cannot permit people to die without care at their end of their lives, whether from COVID-19 or otherwise. Family and friends have in the past helped ensure accountability particularly when a resident is too frail to vocalize concerns or make herself heard and with the significant stresses upon workers and management through COVID-19, this line of accountability is critical (Estabrooks et al. 2020)."

Clearly, primary responsibility for LTC services rests with provincial and territorial governments, but we see across the globe serious efforts to create national coordination for a successful response to COVID-19 in the LTC sector. Canada’s reality is that, without federal financial support, provincial and territorial governments are unlikely to have resources for the high standards that our frail elderly deserve in nursing homes and LTC more broadly. We can look for inspiration to New Zealand, which was able to declare COVID-19 free status on 8 June 2020 (Graham-McLay 2020) (although it continues to see isolated new cases) (BBC News 2020). Australia and South Korea have comparatively favourable results with strong national strategies. The Australian government prioritized the aged care sector for COVID-19—“On the 11th of March, \$440 million was committed to aged care including addressing staff retention and surge staffing, improving infection control. Aged care providers have priority access to the national stockpile of PPE, and health care rapid response teams and staffing

support when an outbreak occur in a facility or in home care” (Low 2020). At the time of this Australian report, nursing homes had <1% of all COVID-19 cases and 17% of all deaths. This compares to Canada’s 81% of all its COVID-19 deaths in nursing homes (CIHI 2020a). South Korea’s aggressive national response to COVID-19 included nationwide monitoring and inspections, cohort quarantines of selected facilities, temporary reimbursement packages, low-cost masks for care workers, and provision of guidelines. At the time of South Korea’s report, only 8.1% of COVID-19 deaths were people in nursing homes, and another 25.9% in LTC hospitals (Kim 2020).

This Working Group, however, takes the position that reform and redesign must tackle not just the pandemic crisis, but also long-standing systemic failures—root causes—of the pandemic crisis in nursing homes in Canada. To fail in doing this leaves us with our currently woefully inadequate LTC system and the certainty that the next crisis will create similar or more catastrophic outcomes. Reform and redesign

- must begin immediately
- are best done within a national framework with provinces/territories and the federal government working together
- must report progress transparently to the public in a timely manner
- must include immediate, mid and long-term targets and ongoing evaluation, in perpetuity, on both quality and safety.

## Workforce recommendations to reform and redesign LTC in Canada

We recommend that if we do nothing else, that immediately and with urgency Canada directs sustained focus, effort and resources to redress the workforce crisis in the LTC sector. Meeting this major challenge will go a long way toward ongoing redesign and reform. It will have an immediate impact on the quality of care and quality of life for vulnerable older adults in nursing homes, on their families, and on the workforce responsible for their care. A high-quality, resilient and supported workforce is, without doubt, the major component of quality.

**We recommend nine steps to solving the workforce crisis in nursing homes, all of which require strong and coordinated leadership at the federal and provincial/territorial levels to implement.**

1. The federal government must immediately commission and act on a comprehensive, pan-Canadian, data-based assessment of national standards for necessary staffing and staffing mix in nursing homes, National standards must encompass the care team that is needed to deliver quality care and should be achieved by tying new federal dollars to those national standards.
2. The Federal government must establish and implement national standards for nursing homes that ensure (a) training and resources for infectious disease control, including optimal use of personal protective equipment and (b) protocols for expanding staff and restricting visitors during outbreaks.
3. The provincial and territorial governments, with the support of new funding from the federal government, must immediately implement appropriate pay and benefits, including sick leave, for the large and critical unregulated workforce of direct care aides and personal support workers. Appropriate pay and benefits must be permanent and not limited to the timespan of COVID-19. Pay and benefits must be equitable across the country and equitable both across the LTC sector and between the LTC and acute care sectors for regulated and unregulated staff.

4. Provincial and territorial governments must make available full-time employment with benefits to all unregulated staff and regulated nursing staff. They should also evaluate the impact on nursing homes of “one workplace” policies now in effect in many nursing homes and the further impact on adequate care in other LTC setting such as retirement homes, hospitals and home care. Provincial and territorial governments must assess the mechanisms of infection spread from multi-site work practices and implement a robust tracking system.
5. Provincial and territorial governments must establish and implement (a) minimum education standards for the unregulated direct care workforce in nursing homes, (b) continuing education for both the unregulated and regulated direct care workforce in nursing homes, and (c) proper training and orientation for anyone assigned to work at nursing homes through external, private staffing agencies.
6. To achieve these education and training objectives, provincial and territorial governments must support educational reforms for specializations in LTC for all providers of direct care in nursing homes, care aides, health and social care professionals, managers and directors of care.
7. Provincial and territorial governments, with the support of federal funds, must provide mental health supports for all nursing home staff. In addition to extraordinarily stressful pandemic working conditions, these staff are experiencing significant deaths among the older adults they have known for months and years, and among colleagues. They are grieving now, and this will continue.
8. Federal support of the LTC sector must be tied to requirements for data collection in all appropriate spheres that are needed to effectively manage and support nursing homes and their staff. Data collected must include resident quality of care, resident quality of life, resident and family experiences, and quality of work life for staff. Data must be collected using validated, appropriate tools, such as tools suitable for residents with moderate to severe dementia. Captured data must address disparities and compounding vulnerabilities among both residents and staff, such as race, ethnicity, language, gender identity, guardianship status, socioeconomic status, religion, physical or intellectual disability status, and trauma history screening.
9. Data collection must be transparent and at arm’s length. Provincial and territorial governments must evaluate and use data to appropriately revisit regulation and accreditation in nursing homes. They must take an evidence-based and balanced approach to mandatory accreditation, as well as to regulation and inspection of nursing homes. They must engage the LTC sector in this process, particularly the people receiving care, their families, managers and care providers.

We do not need another whole-system commission, another inquiry, another report or to have the armed forces be the best or only alternative to stem a preventable crisis in nursing homes. What we do need is a transparent national action plan with strong and coordinated national and provincial/territorial leadership, broad stakeholder input, responsibilities, accountabilities and the ability to bring resources to bear as needed. Such an action plan must of course link with other relevant national strategies, such as the Public Health Agency of Canada’s dementia strategy.

## Canada’s choice

Any recommendations and all reform and redesign of the residential LTC sector must recognize and place at the core of all thinking and action that these settings are home for their residents. In most cases, their last home. Quality of life and death must not be sacrificed with neglect, when regulation is reasonable and warranted. They must also not be sacrificed with rigid over-regulation when risk tolerance is warranted. Good social and health care means that older adults in nursing homes experience a good quality of life and a good death. These are indispensable ingredients of our duty to care in nursing homes and must be primary.

We have failed our older adults by not keeping pace with care demands, by assuming that care of the frail older adults in nursing homes is “just basic care” and anyone can do it with little or almost no

training and education, by ignoring the highly gendered nature of nursing home care, by “holding the line” on resources. We have failed by believing that the solution lies in a less than coherent approach to regulation—high regulation in some areas that may for example, infringe on individual rights and freedoms, and no regulation in others such as consistent education standards for direct care staff. Most shamefully, we have failed by not hearing the voices of older Canadians in their last phase of life. Canadian nursing homes had generally been able to “just manage”, something far from adequate before the pandemic.

Then came COVID-19, a shock wave that cracked wide all the pre-existing fractures in our nursing homes. It precipitated, in the worst circumstances, loss of life, along with high levels of physical, mental and emotional suffering for our older adults. Those unnecessarily lost lives had value. Those older adults deserved the last years of their lives and they deserved a good death. We failed them. We have a duty and a responsibility to fix this—not just to prepare for the second wave of COVID-19 and other future infectious diseases but a root-and-branch overhaul of the LTC sector that helped that crisis wreak such avoidable and tragic havoc. We can take steps to immediately begin restoring the trust we have broken. It’s a matter of choice.

Both the immediate and the long-term challenges in nursing homes and their solutions are complex. Comprehensive, integrated and evidence-informed change will take time. Many real and urgent priorities will appear and compete as action progresses. As a country we will be required to ask: “What choices are we willing to make so that none of us needs to fear the quality of life and care that may await us in a nursing home?” Breaking out of long-established patterns is hard and the easiest choice for many will be to not disrupt the status quo. To succeed to radically transform nursing homes we must lead with courage and resolve, making the necessary choices wisely.

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## Author contributions

CAE, SES, CMF, JK, PA, GJD, VB, FD, JLS, and MCW conceived and designed the study. CAE, PA, and JLS performed the experiments/collected the data. CAE, SES, CMF, JK, PA, GJD, VB, FD, JLS, and MCW analyzed and interpreted the data. CAE, CMF, and JK contributed resources. CAE, SES, CMF, JK, and FD drafted or revised the manuscript.

## Competing interests

The authors have declared that no competing interests exist.

## Data availability statement

All relevant data are within the paper.

## Supplementary materials

The following Supplementary Material is available with the article through the journal website at doi:[10.1139/facets-2020-0056](https://doi.org/10.1139/facets-2020-0056).

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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