

# Life and Death in Long-Term Care: Are We Learning the Wrong Lessons from COVID-19?

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## ABOUT THIS STUDY

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# Key Findings

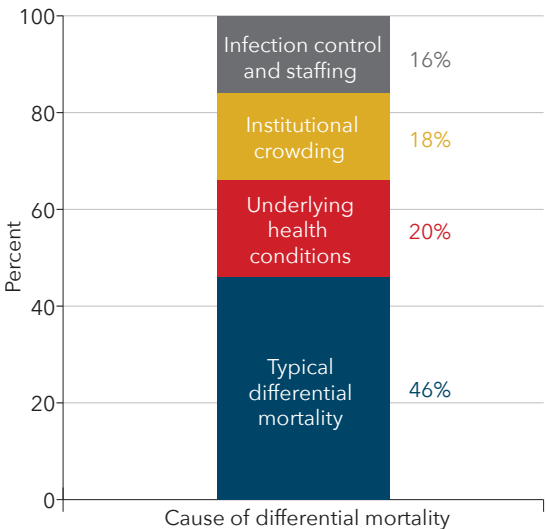
The COVID-19 pandemic has had a devastating effect on long-term care (LTC) homes. Governments and policymakers should use the experience to create a better model of care that puts the needs and interests of recipients first.

This study presents a novel approach to measuring the performance of long-term care institutions during the pandemic, and identifies the factors behind their performance. Based on the findings, it proposes three areas for action that could inform federal, provincial and territorial government discussions on how to improve long-term care in Canada.

Instead of using the most common metric for measuring the performance of LTC institutions – the percentage of long-term care deaths relative to total deaths – the report measures the change in differential mortality between a nonpandemic year, 2018, and the first wave of the pandemic in 2020. Differential mortality compares deaths in institutions with deaths in similar age groups living in the community. This approach reflects the fact that the risk of dying in an institution is higher than in the community, even in nonpandemic years. The report finds that the pandemic approximately doubled the risk of dying among residents of long-term care homes compared to comparable groups in the community.

### One third of the differential mortality in institutions can be attributed to the way institutions are organized and funded

#### Factors behind COVID-19 differential mortality



Source: Authors' compilation  
Note: This chart uses the 10-year age bands for age-specific mortality in the calculation of differential mortality.

The report concludes that one third of the differential mortality can be attributed to factors determined by the way institutions are organized and funded, such as crowding, and a lack of adequate staffing and prevention and control practices. The remainder can be attributed to factors outside institutional control, including the higher COVID-related mortality risk among residents with certain underlying illnesses.

The authors caution governments against drawing the wrong lessons from the pandemic experience and enforcing a rigid and highly monitored form of care based solely on preventing death. It argues that this would ultimately lower the quality of life of residents. While preventing mortality among LTC residents should remain a top priority, the

report's analysis indicates that other factors should also be considered in implementing LTC reform. It proposes three areas for government action:

- Develop clear guidance for long-term care institutions on the appropriate balance between preventing death and supporting quality of life
- Improve the efficiency of long-term care through efforts that increase the use of home care and allow institutional specialization
- Estimate costs associated with long-term care in the coming decades, including home care, and identify mechanisms to finance those costs

# Faits saillants

La pandémie de COVID-19 a eu un effet dévastateur sur les établissements de soins de longue durée (SLD). Les gouvernements et les décideurs politiques devraient profiter de cette expérience pour créer un meilleur modèle de soins qui place les besoins et les intérêts des bénéficiaires au premier plan.

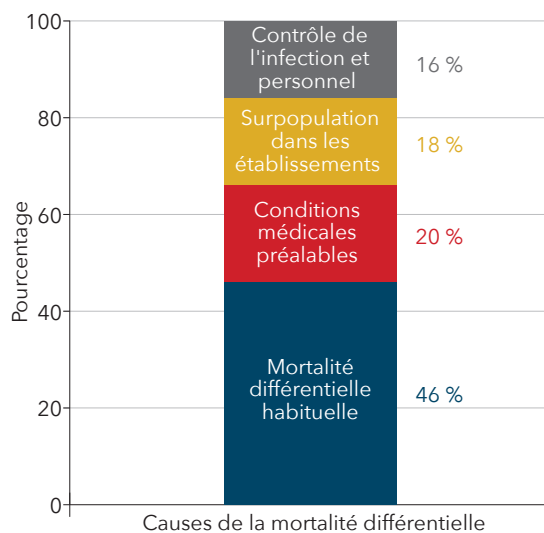
Cette étude présente une nouvelle approche pour mesurer la performance des établissements de SLD pendant la pandémie, et identifie les facteurs à l'origine de leur performance. Sur la base de ces résultats, elle propose trois domaines d'action qui pourraient alimenter les discussions des gouvernements fédéral, provinciaux et territoriaux sur la manière d'améliorer les SLD au Canada.

Au lieu d'utiliser la mesure la plus courante pour évaluer les performances des établissements de SLD – le pourcentage de décès liés aux SLD par rapport au nombre total de décès – le rapport mesure l'évolution de la mortalité différentielle entre une année non pandémique, 2018, et la première vague de la pandémie en 2020. La mortalité différentielle compare les décès en institution avec les décès de groupes d'âge similaires vivant dans la communauté. Cette approche reflète le fait que le risque de mourir dans une institution est plus élevé que dans la communauté, même dans les années non pandémiques. Le rapport constate que la pandémie a approximativement

doublé le risque de décès chez les résidents des établissements de SLD par rapport aux groupes comparables dans le reste de la société.

## Un tiers de la mortalité différentielle dans les établissements peut être attribué à la manière dont ils sont gérés et financés

### Causes derrière la mortalité différentielle durant la pandémie



Le rapport conclut qu'un tiers de la mortalité différentielle peut être attribué à des facteurs déterminés par la manière dont les institutions sont organisées et financées, tels que la surpopulation, et le manque de personnel adéquat et de pratiques de prévention et de contrôle. Le reste peut être attribué à des facteurs échappant au contrôle des institutions, notamment le risque de mortalité plus élevé lié à la COVID chez les résidents souffrant de certaines maladies sous-jacentes.

Les auteurs mettent en garde les gouvernements contre le risque de tirer les mauvaises leçons de l'expérience de la pandémie et d'imposer une forme de soins rigide et

Source : Données recueillies par les auteurs.  
Note : Cette figure présente des tranches de 10 ans pour la mortalité par âge dans le calcul de la mortalité différentielle.

hautement surveillée, fondée uniquement sur la prévention des décès. Ils affirment qu'une telle démarche aurait pour effet de réduire la qualité de vie des résidents. Si la prévention de la mortalité chez les résidents de SLD doit rester une priorité absolue, l'analyse du rapport indique que d'autres facteurs doivent également être pris en compte dans la mise en œuvre de la réforme des SLD. Il propose trois domaines d'action pour le gouvernement :

- Élaborer des orientations claires à l'intention des établissements de SLD sur l'équilibre approprié entre la prévention de la mort et le soutien de la qualité de vie ;
- Améliorer l'efficacité des SLD par des efforts visant à accroître le recours aux soins à domicile et à permettre la spécialisation des établissements ;
- Estimer les coûts associés aux SLD dans les décennies à venir, y compris les soins à domicile, et identifier les mécanismes de financement de ces coûts.



## INTRODUCTION

The outbreak of the COVID-19 pandemic in early 2020 had a devastating effect on long-term care (LTC) homes. However, governments and long-term care institutions should take care to avoid taking away the wrong lessons from the experience. While reducing mortality in LTC homes should remain a priority, so should enhancing the quality of life of residents.

This study presents a novel approach to measuring the performance of long-term care institutions throughout the pandemic, and the factors behind their performance. Instead of using the most common metric – the percentage of long-term care deaths relative to total deaths – we measure the change in differential mortality between a nonpandemic year, 2018, and the first wave of the pandemic in 2020. Differential mortality compares deaths in institutions with deaths in similar age groups living in the community. This approach accounts for the fact that the risk of dying in an institution is much higher than in the community even in nonpandemic years.

We find that the pandemic approximately doubled the risk of dying among residents of long-term care homes compared to similar-aged individuals living in the community. The study assesses the factors behind the higher differential mortality by isolating the factors outside the control of institutions, such as higher COVID-related mortality risk for residents with certain underlying illnesses.

The results point to actions that governments and institutions can take to limit higher institutional mortality, but we caution against a rigid and highly monitored form of care that would negatively affect the quality of life of residents.

## INDICATORS OF LONG-TERM CARE PERFORMANCE

News headlines during the early days of the pandemic focused on the high number of deaths in Canadian long-term care institutions. A report from the Canadian Institute for Health Information (CIHI) shows that 79 per cent of deaths due to COVID-19 in Canada during the first wave of the pandemic and 60 per cent in the second wave were in long-term care institutions (CIHI, 2021). This percentage was much higher than in other OECD countries in the first wave, and was interpreted as evidence of the poor performance of Canadian long-term care institutions (CIHI, 2020). Many calls for action were prompted by these dismal numbers.

However, this interpretation is misleading because it focuses on one statistic: the proportion of deaths due to COVID-19 in institutions relative to the total number of deaths due to the coronavirus (in institutions and the community). This statistic can be very high even when the mortality rate in institutions is not, if the mortality rate due to the coronavirus in the community is very low. The focus on this statistic is understandable because it is easy to collect, but it is not the most accurate.

In fact, the overall mortality rate in Canada due to COVID-19 was very low compared to other countries. A study by Razak et al. (2022) shows that Canada had the second lowest rates of cumulative COVID-19 deaths and excess mortality across a group of 10 wealthy countries. Only Japan performed better. Such a low mortality rate in the community inflates the proportion of deaths in long-term care institutions.

A better international comparator of the performance of the long-term care sector is the mortality rate in institutions (see table 1). Data published by two sources – the International Long-Term Care Policy Network (ILPN) (Comas-Herrera et al., 2021) and Sepulveda et al. (2020) – show that mortality in Canadian institutions was lower than in Spain, the U.K., Italy, Belgium, Ireland, the U.S., Sweden, the Netherlands, France,

**Table 1. Mortality rates in Canadian institutions during the pandemic were lower than in several countries**

*Mortality in LTC institutions during the pandemic, select countries*

Country	Mortality in institutions per 1,000 people	
	International Long-Term Care Policy Network (January 2021)	Sepulveda et al. (July, 2020)
Canada	26	16
Belgium	94	36
Slovenia	82	n.a
Spain	79	53
U.K.	72	42
Italy	n.a	52
U.S.	72	23
Sweden	57	21
Netherlands	54	16
France	50	22
Ireland	48	32
Finland	42	n.a
Australia	33	n.a
Portugal	23	n.a
Denmark	18	5
Germany	17	4
Norway	8	n.a
New Zealand	0	n.a

Sources: Comas-Herrera et al. (2021); Sepulveda et al. (2020).

Note: Canada is among the countries that adopted a broad definition of mortality due to COVID-19, including confirmed and probable deaths. Denmark and Germany counted confirmed deaths only, which may explain their lower mortality rates.

Finland and Australia. The only countries with lower mortality in LTC institutions were Portugal, Denmark, Germany, Norway and New Zealand. Therefore, it can be said that Canada did no worse than comparable countries in terms of COVID-19 related mortality in institutions during the first year of the pandemic. This is not to suggest that the level of mortality in Canadian LTC homes is not a concern. However, it is worth noting that Canada performed better than a number of other countries.

## ASSESSING THE EFFECTS OF THE PANDEMIC ON MORTALITY IN INSTITUTIONS

Even though mortality in Canadian long-term care institutions was no worse than in many comparable countries, it was worse than in nonpandemic years. Assessing how much worse it was would help determine what policy changes are warranted to limit mortality rates.

***Differential mortality is the ratio of mortality in institutions to mortality among similar age groups in the community. If the ratio is greater than one, it indicates that individuals living in institutions are more likely to die than individuals living in the community.***

To assess the impact of COVID-19 on mortality in institutions, we compare the differential mortality between individuals in institutions and similarly aged people in the community during the first year of the pandemic to the differential mortality prior to the pandemic.

Institutional mortality is typically higher than in the community (Fisman et al., 2020; Auditor General of Ontario, 2021). In Canada the life expectancy of a resident entering a facility in the late 1990s was around one year.<sup>1</sup>

To determine how much higher the mortality differential was in 2020 compared to prepandemic years, we standardized the differential by age. The population of residents in long-term care is much older than the general population, and COVID-19 hit older individuals much harder. It would be inaccurate to calculate mortality differentials without taking age into account. Therefore, we calculated an age-standardized mortality differential for two years (2018 and 2020); the differential is the ratio of observed to expected deaths in Canadian institutions. To calculate

<sup>1</sup> Personal calculations of the authors and Senay Asma based on analysis of the National Population Health Survey, longitudinal component for the whole country, in the late 1990s and early 2000s. More recent data from the Translating Research in Elder Care (TREC) team on three western provinces (Hoben et al., 2019) suggest length of stay in institutions of just over a year in Edmonton and Calgary, and 2.4 years in Winnipeg.

the expected number of deaths, we applied age-specific mortality rates<sup>2</sup> of the general population (for all causes of death in 2018 and COVID-19 deaths in 2020) to the age distribution of residents of long-term care institutions in 2018-19 (see Appendix A for details of the methodology). The change in differential, calculated as the ratio of these two ratios, tells us the impact of COVID-19 on mortality in institutions relative to the community. We then decompose this impact based on what can be attributed to the health of residents and what can be attributed to institutions themselves, such as the way they prevent and handle outbreaks through staffing, control of crowding and preventative practices.

The lack of data on mortality and morbidity in institutions is a significant challenge for researchers (see Appendix C). While Statistics Canada conducts an annual survey of institutions, the institution-level data are not made available to the research community, which must rely on aggregate-level statistics. Researchers are also not able to get stable and reliable numbers of residents of Canadian long-term care institutions. Given this lack of data, we use a two-step method to standardize mortality rates by age and health status:

- **Step 1: Interpolation** – To calculate the age-standardized expected number of deaths in 2020, we use the age-specific mortality rates due to COVID-19 in the general population published by the Canadian government for the first wave and the distribution of the population in institutions by age group in fiscal 2018-19 published by CIHI.<sup>3</sup> We then do the same with age-specific mortality for all causes<sup>4</sup> and the same age distribution of residents to get an age-standardized expected number of deaths in 2018. Since the age groupings for the two data sets are not the same, we use linear interpolations to match the age categories (see Appendix A for details on the interpolation method).
- **Step 2: Extrapolation** – Since not all institutions report the age distribution of their residents, we use data from jurisdictions where it is available to extrapolate to the entire country. To account for gaps in data in the Maritime provinces, Quebec, Nunavut and the Northwest Territories, we use an age-specific mortality ratio (using institutional discharges as a proxy for deaths) from the provinces and territory where data is available. We extrapolate it to the whole country based on published statistics on the number of residents (or beds) in Canada compared to that observed in the subset of provinces and territories where data is available (see Appendix A for detail on the extrapolation method).

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<sup>2</sup> The rates were calculated as of November 2, 2020, using the number of deaths due to COVID-19 (confirmed or probable) in the total population, by age groups (0-19, 10-year categories up to 80+), published by the Canadian government (<https://health-infobase.canada.ca/covid-19/?stat=num&measure=deaths#a2>). We then divided the number of deaths by the size of each age group in 2020, published by Statistics Canada (<https://health-infobase.canada.ca/covid-19/>).

<sup>3</sup> CCRS quick statistics, "Profile of residents in residential and hospital-based continuing care 2019-20," (<https://www.cihi.ca/en/quick-stats>)

<sup>4</sup> Statistics Canada, life table, 2017-19.

**Table 2. During the first six months of the pandemic, institutional deaths were more than nine times higher than those in the community**

*Change in differential mortality between institutions and the general population in 2018 and during the first wave of the pandemic*

	10-year age bands for age-specific mortality risks	5-year age bands for age-specific mortality risks
<b>Differential mortality due to COVID 19 in the first pandemic wave</b>		
E = Expected COVID-19 deaths (based on age-specific COVID-19 mortality rates in the first wave)	632	668
O = Observed COVID-19 deaths in the first wave (CIHI statistics)	6,080	6,080
O:E = Differential mortality due to COVID-19	9.62	9.10
<b>Differential mortality in 2018</b>		
E = Expected deaths due to all causes in 2018 (based on age-specific mortality rates from Statistics Canada)	32,089	32,089
O = Observed deaths due to all causes in 2018 (using institutional discharges as a proxy)	141,767	141,767
O:E = Differential mortality due to all causes	4.42	4.42
<b>Change in differential mortality</b>	<b>2.2</b>	<b>2.1</b>

Sources: Expected COVID-19 Deaths in Institutions: CIHI, *Profile of Residents in Residential and Hospital-based Continuing Care 2019-20*, <https://www.cihi.ca/en/quick-stats>; Statistics Canada, *Population estimates on July 1st, by age and sex*, <https://doi.org/10.25318/1710000501-eng>.

Observed COVID-19 Deaths in the first wave: CIHI (2021).

Expected deaths all causes in 2018: personal calculations based on age-specific mortality rates for the Canadian population from Statistics Canada.

Observed deaths all causes in 2018: CIHI *Profile of Residents in Residential and Hospital-based Continuing Care, 2018-19*, <https://www.cihi.ca/en/quick-stats>.

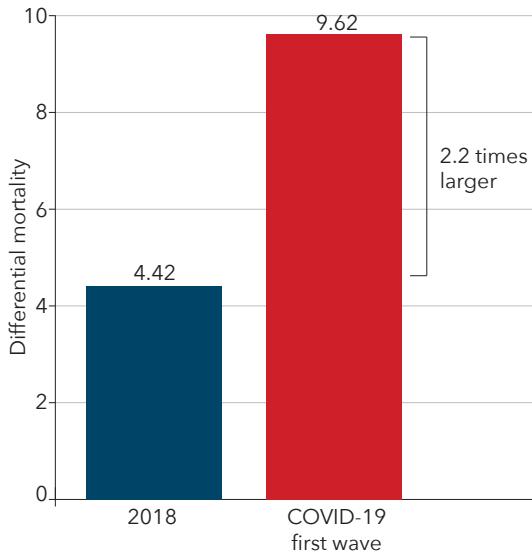
See Appendix A for further detail on methodology.

In table 2, we present the results of simulations based on the two steps described. We ran two sets of simulations. The first uses the age-specific mortality rates as published for 10-year age bands. The second uses interpolated age-specific mortality risks during the first wave of COVID-19 for five-year age bands (we kept the 10-year age bands for the all-causes mortality risks). We did this because the relationship between age and mortality due to COVID-19 was very steep in the first wave of the pandemic, and 10-year age bands might not accurately reflect the role of age. The interpolation uses a simple linear regression formula (see Appendix A for details on this second interpolation).

Table 2 shows that in 2018, institutional deaths were an estimated 4.4 times higher than that among a similar-aged population in the community. During the first six months of the pandemic, institutional deaths were more than nine times higher. The differential mortality between institutions and the community during the first six months of the pandemic was therefore double the normal rate (see figure 1). Sensitivity analyses using alternative numbers of residents for the extrapolation show that differential

**Figure 1. The differential mortality rate between institutions and the community was more than double in the first wave of the pandemic**

*Differential mortality between institutions and the community in the first wave of the pandemic and in 2018*



Source: Authors' compilation

Note: This chart uses the 10-year age bands for age-specific mortality in the calculation of differential mortality.

by New Zealand at 48 per cent (Connolly et al., 2014), Norway at 44 per cent (Kalseth & Halvorsen, 2020), France and Australia at around 35 per cent (Pennec et al., 2013; Palliative Care Australia, 2017), England at 26 per cent and Wales at 21 per cent (Office of National Statistics, 2020a; 2020b). It could therefore be the case that Canada has too high a mortality in its long-term care institutions (compared to other countries), that the pandemic revealed.

## FACTORS INFLUENCING MORTALITY IN INSTITUTIONS

To reduce higher mortality rates in institutions, we need to have a better understanding of the underlying factors. We need to understand what mortality tells us about practices in institutions and whether deaths were preventable by actions that institutional managers could have implemented or if the mortality differential in institutions reflects the higher level of frailty of residents compared to those of the same age living in the community.

We suggest that the increase in differential mortality during the pandemic is the result of four factors: (1) residents are more likely than individuals of the same age living in the community to suffer from conditions that increase the fatality rate of COVID-19;

mortality could be as much as 2.5 times higher.

Differential mortality in nonpandemic years may also not be an appropriate baseline, as it implies that it is acceptable. It might be the case that, in nonpandemic years, too many institutional residents die compared to similar aged people in the community, and that this is a feature specific to Canada and not "natural" or "universal."

International comparisons can help gauge the performance of our institutional long-term care sector in nonpandemic years. The proportion of all deaths among residents of LTC institutions was close to 50 per cent in Canada in a prepandemic year; among countries for which we could find the same statistic, Canada had the highest proportion, followed

(2) residents cannot properly isolate because they live in institutions that are prone to outbreaks (especially if rooms have more than two beds); (3) institutions did not provide enough support (staff hours) to residents; and (4) institutions did not implement necessary infection prevention and control procedures (Brown et al., 2021; Stall et al., 2020; Auditor General of Ontario, 2021). There is little that can be done to address the first factor, but the others can be influenced by the actions and behaviours of those owning and managing these institutions.

Our next analysis tries to decompose the increase in differential mortality between the first factor and the rest. To break down the factors behind the higher differential mortality, we subtract the differential mortality risk during nonpandemic years from that during the first wave of the pandemic ( $9.62 - 4.42 = 5.2$ ). We assume that the mortality differential in 2018 is due to the health of residents and the effects of living in an institution (which increases the probability of outbreaks of infectious diseases in general). The typical differential mortality is therefore 46 per cent of the relative risk during the first wave of the pandemic ( $4.42 \div 9.62 \times 100$ ).

This allows us to focus on decomposing the factors behind the remaining 54 per cent of differential mortality ( $5.2 \div 9.62 \times 100$ ). To simplify the analysis, we consider two primary factors:

- Health concerns that increase the risk of dying from COVID-19: The prevalence of chronic conditions among the residents of institutions that increase fatality when contracting COVID-19
- Institutional factors: Aspects such as crowding, lack of staffing, and prevention and control practices that increase the likelihood of infection and reduce the quality of care

It is possible to estimate the degree to which residents' health contributed to differential mortality using data on COVID-19 case fatality among individuals suffering from certain health conditions (World Health Organization, 2020; Zuin et al., 2021) and data on the prevalence of these conditions in institutions and the community (Auditor General of Ontario, 2021; Government of Canada, n.d.b). (See Appendix B for a detailed description of this methodology).

Table 3 shows the results of the analysis. Two health conditions are much more prevalent in institutions than in the community: cardiovascular disease (CVD) and dementia. Simulations of COVID-19 mortality rates linked to the higher prevalence of frailty produce an estimated differential mortality of 1.9. This represents about 20 per cent of the differential mortality due to COVID-19 of residents in institutions relative to community dwellers ( $1.9 \div 9.62 \times 100$ ).

The remaining 34 per cent of differential mortality due to COVID-19 that is not explained by typical differential mortality or the higher prevalence of frailty in institutions could be attributed to institutional factors that increase the risk of contracting and dying from COVID-19. Several studies and reports have identified three main

**Table 3. Cardiovascular disease and dementia are more prevalent in institutions than in the community***Simulations of COVID-19 mortality rates in institutions and in the community based on differences in prevalence of health conditions*

	Fatality rate	Prevalence in institution	Prevalence in community, same age	Simulated institution <sup>1</sup>	Simulated community <sup>1</sup>	Differential mortality linked to health (Observed deaths: Expected deaths given higher prevalence of frailty) <sup>2</sup>
Cardiovascular disease (CVD)	0.132	0.759	0.343	0.104	0.055	1.90
Diabetes	0.092	0.280	0.285	n.a	n.a	n.a
Hypertension	0.084	0.641	0.749	n.a	n.a	n.a
Respiratory	0.080	0.183	0.238	n.a	n.a	n.a
Cancer	0.076	0.097	n.a	n.a	n.a	n.a
None	0.014	n.a	n.a	n.a	n.a	n.a
Dementia	0.050	0.632	0.142	0.037	0.019	1.92

Sources: World Health Organization (2020), Zuin et al. (2021), Auditor General of Ontario (2021) and Statistics Canada (2021).

Notes:

<sup>1</sup> For CVD and dementia, we ran simulations that reflected the higher prevalence of these conditions in institutions.

<sup>2</sup> Differential mortality due to frailty is likely underestimated given that some residents may suffer from multiple conditions and there is no case-fatality data for combinations of conditions.

institutional factors: crowding, insufficient staffing, and insufficient prevention and control practices.

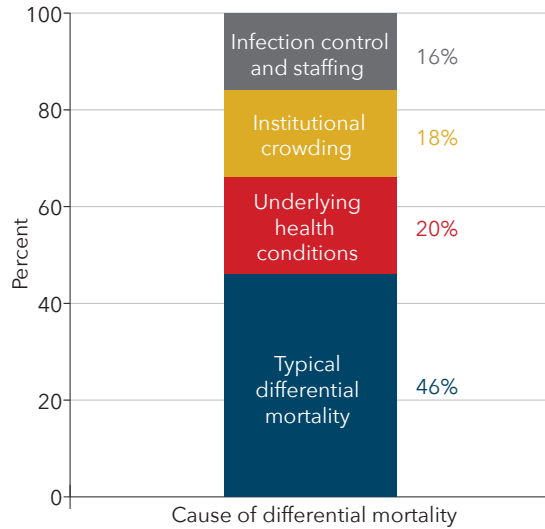
Reducing the number of beds used per room has been identified as an important measure to prevent the spread of COVID-19. Brown et al. (2021) find that banning rooms with three or four beds in Ontario institutions would have prevented 18 per cent of deaths during the first wave. This could be an overestimate for other provinces and territories, as Ontario lags in efforts to reduce this practice. Ontario relies more heavily on private for-profit institutions than other provinces, and these institutions tend to have more three- or four-bed rooms than not-for-profit or publicly owned facilities.

If we attribute roughly 18 per cent of deaths to crowding, that would leave 16 per cent of differential mortality caused by insufficient staffing and prevention and control practices. Military officials called in to fill gaps in long-term care institutions in Ontario during the early days of the pandemic reported significant concerns regarding a lack of staffing, insufficient staff training and ineffective infection control practices (TVO Today, 2020). Many of these issues are linked to a lack of funding.



## Figure 2. One third of the differential mortality in institutions can be attributed to the way institutions are organized and funded

### Factors behind COVID-19 differential mortality



Source: Authors' compilation

Note: This chart uses the 10-year age bands for age-specific mortality in the calculation of differential mortality.

Considering how institutions are organized and funded and the effect on mortality is not new. Evidence shows that these factors contribute to differences in mortality across provinces and ownership status (Liu et al., 2020; Stall et al., 2020). Our results complement these studies by estimating that these differences could explain up to 34 per cent of the differential mortality in institutions due to COVID-19: 18 per cent for crowding and 16 per cent for infection control practices and staffing (figure 2).

## MAPPING A PATH FORWARD

There is no doubt that the pandemic had a devastating impact

on long-term care institutions in Canada. Our analysis shows that COVID-19 approximately doubled the relative risk of dying for residents in an institution compared to similar-aged individuals living in the community.

However, government and policymakers should take significant care not to draw lessons exclusively from mortality rates. Our analysis shows that mortality has always been very high in long-term care facilities, and while COVID-19 exacerbated the situation, it was not solely responsible for the differential mortality between those who live in an LTC home and those who live in the community. Our analysis of the underlying factors driving differential mortality during the pandemic's first wave indicates that one-third of differential mortality can be linked to things facilities could have done had they had adequate funding. However, these systemic issues in care provision are long-standing and not exclusive to the pandemic.

Preventing mortality should therefore not be the sole motivation for reform of the institutional care sector or of overall approaches to long-term care. Instead, drawing on existing literature, we propose three areas for government action in response to challenges revealed by the pandemic:

- Develop clear guidance for long-term care institutions on the appropriate balance between preventing death and supporting quality of life

- Improve the efficiency of long-term care through efforts that increase the use of home care and allow institutional specialization
- Estimate costs associated with long-term care in the coming decades (including home care) and identify mechanisms to finance those costs

### **Develop clear guidance and performance measures for long-term care institutions that reflect an appropriate balance between preventing death and supporting the quality of life of residents**

Governments play a critical role in regulating long-term care institutions and measuring their performance. The approach they take will determine if institutions become highly micromanaged and risk averse or more autonomous and focused on residents' quality of life.

Finding the right balance won't be easy. No one wants to put residents unduly at risk, but governments need to help institutions identify how much risk is acceptable while striving to improve residents' quality of life. There will not be standard, one-size-fits-all answers, but overarching guidance could support effective institution-led innovation in their approaches to care.

The Standards Council of Canada (SCC), the Health Standards Organization (HSO) and the Canadian Standards Association (CSA Group) have worked collaboratively to develop new national standards for long-term care services and operations (HSO, 2022). The standard recently published by CSA Group addresses the design of facilities, operations, and infection prevention and control, among other things. The group states that the standard is "designed to balance the safety of residents with their right to live in dignity," and calls on LTC homes to adopt a model of "person-centred care" (CSA Group 2022, 6). A complementary standard released by the HSO in January 2023 provides guidance on promoting good governance, upholding resident-centred care, enabling a meaningful quality of life for residents, ensuring high quality and safe care, fostering a healthy and competent workforce, risk management, and promoting a culture of improvement and learning (HSO, 2023). Based on the reaction from federal and provincial governments to the standards when they were released, they are unlikely to be mandatory.

However, a significant part of the implicit guidance provided to institutions comes from metrics governments use to measure and compare performance, which may or may not be specified in legislation. If facilities are monitored and financially rewarded based on their ability to prevent adverse events or death, they may focus solely on limiting or preventing those behaviours that increase risk of death yet may improve quality of life.

It may be tempting for governments, after the increase in mortality and the obvious failures of some institutions to respond to outbreaks during the pandemic, to micromanage institutions, mandate more rules and standards, and demand more data from institutions.

However, we caution that an overemphasis on preventing falls, hospitalization or mortality will require a relatively rigid and monitored way of life. Institutions may also

be tempted to use pharmaceutical treatments to prevent hazardous behaviours: the Health Quality Ontario website (<https://www.hqontario.ca>) shows that 19 per cent of residents with no history of psychosis were given anti-psychotic medication in 2020-21 (down from a high of 35 per cent in 2011-12). These actions may seem perfectly justifiable from an institutional perspective if the goal is to prevent adverse events, such as falls or hospitalizations, which are used to measure institutional performance.

Even in cases where an initiative appears to support both reduced mortality and enhanced quality of life, the motivation behind the initiative will be important. For example, it has been argued that it is crucial to provide each resident a private room to prevent outbreaks. However, if not managed carefully, such a measure could add to the isolation and loneliness of residents. Staff would need to make an additional effort to provide opportunities for residents to socialize. Institutions could also take advantage of private rooms to improve resident care, allowing personal support workers (PSWs) to spend time speaking with residents one-on-one without fear of being overheard or having to monitor several residents at the same time. If done well, having a private space could enhance a resident's sense of self-dignity and autonomy, and help make them feel at home rather than as

**Figure 3. A rigid and highly monitored approach to regulating long-term care homes can inhibit residents' quality of life**

*Quality of life domains for long-term care residents*



Source: Adapted from Kane et al. (2003).

temporary occupants in an institution. This approach would be in line with the quality-of-life domains for nursing home residents identified by Kane et al. (2003), which include security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being and functional competence (figure 3).

A rigid and monitored approach to institutions can work against quality of life goals. Residents might enjoy taking a nap during lunch time and catching up later on less-than-perfect food (from a nutritional perspective). They might enjoy going out for a walk even though the terrain is slippery. In an ideal world, however, long-term care institutions would have appropriate resources allowing residents to perform these activities safely. And they might enjoy drinking a glass of wine. Kane et al. (2003) argue that enhancing quality of life in institutions will require accepting a certain amount of risk. Attention should therefore be placed on exploring how to weigh the risks and benefits to quality of life on a patient-by-patient basis.

An emphasis on quality of life in long-term care is advocated by many, including academics, resident advocates, care providers and, more recently, governments (Taylor & Keefe, 2021). The Ontario Long-Term Care Association (OLTCA), which represents all facilities in the province, advocates for a resident-centred model rather than a service-centred one (OLTCA, 2015). In a service- or institutional-centred approach, staff are required to perform a certain number of tasks in a given amount of time and are monitored and compensated for doing so. In a resident-centred model, staff are tasked with looking after the well-being of a specific number of residents and can spend more time with those residents who are more in need (psychologically or physically).

A resident-centred model would require enough financial and human resources to allow staff to pay attention to the physical, emotional and social well-being of residents, including the provision of what is sometimes called “emotion-centred care,” meaning care in which the PSW or nurse takes time to listen to the feelings and concerns of residents and provides a human response respecting the emotions, dignity and sense of agency of the resident.

The underlying idea of resident-centred or emotion-centred care is that the PSW or nurse will consider the resident as a whole person rather than a series of issues to resolve and responses to provide; for that reason, it is sometimes called a holistic

**Table 4. A resident-centred care model considers the whole person**

*Characteristics of service-centred care versus resident-centred care*

Service-centred care	Resident-centred care
Aimed at preventing risk (e.g., mortality, falls, hospitalizations)	Aimed at supporting quality of life
Rigid schedule	Flexible schedule
Primarily clinical interaction with staff	Primarily emotional interaction with staff
Staff are provided tasks to complete in a given time frame	Staff are provided residents to care for, with flexibility to respond to specific needs

approach and it has been recommended by the Ontario commission on long-term care and COVID-19 (Marrocco et al., 2021). Innovative models of care along those lines, such as the butterfly model or the greenhouse project<sup>5,6</sup> are already developed, and demonstration projects show promise in terms of the well-being of residents and staff retention (Armstrong et al., 2019; Zimmerman et al., 2016).

Part of the challenge for governments in shifting to a resident-centred model of care that emphasizes quality of life is that it would make institutional performance much more difficult to measure. Under the current system, proxies for quality are often linked to the clinical aspect of quality of service.<sup>7</sup> A facility whose residents are less likely to end up in the emergency room or to fall is considered “better quality,” in the sense of providing better care to their residents. These measures are favoured by governments because they are objective and more easily defined and measured.

It is much harder to measure psychological well-being or satisfaction, even though this is crucial to shift the institutional culture away from the medical model to one that is person centred (Abbott et al., 2018). Measures that aim to quantify these aspects are also considered less reliable as indicators of quality. For example, 40 per cent of residents cannot answer a questionnaire directly and would have to do it through a proxy, usually a relative. This defeats the purpose because well-being is inherently a subjective quality and almost impossible to be assessed by a proxy. Among the 60 per cent of residents who can answer a questionnaire, it is difficult to assess if their answers truly reflect their psychological well-being or, even more important, to what degree their experiences in the facility contribute to it (Kehyayan et al., 2015). There are several such questionnaires, each with their strengths and weaknesses, that reflect the perception of quality held by those who created it (Morris et al., 2018; Shippee et al., 2015).

One solution may be to give greater autonomy and flexibility to institutions and their employees to implement their own definition of quality and strike the appropriate balance between safety and quality of life, with the goal of enhancing residents’ well-being while respecting their preferences and those of their relatives. The HSO guidelines recommend developing a risk management plan, in collaboration with residents, their substitute decision makers and the team of essential care partners that balances residents’ autonomy with the safety of others.

More autonomous models exist in health care: we do not micromanage doctors and we tend to trust them to deliver care with the best interest of their patients at heart. That does not mean they can do whatever they want without sanctions, but we tend to trust first and sanction when necessary.

<sup>5</sup> Armstrong et al., “Models for Long-term Residential Care: A Summary of the Consultants’ Report to Long-Term Care Homes and Services, City of Toronto.”

<sup>6</sup> Zimmerman et al., “New Evidence on the Green House Model of Nursing Home Care: Synthesis of Findings and Implications for Policy, Practice, and Research”, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5338207/>.

<sup>7</sup> See for instance, in Ontario: <https://www.hqontario.ca/system-performance/long-term-care-home-performance>.

Such a model may be more challenging to implement in for-profit long-term care institutions that have a strong profit motive in reducing costs per resident. Therefore, to give more autonomy to PSWs, nurses and institutions, it may be necessary to limit the number of for-profit long-term care institutions.

As institutions react to lessons learned from the pandemic, governments should guide their approach by articulating the appropriate balance between preventing mortality and supporting quality of life. Measures used to evaluate institutional performance should also reflect a resident-centred approach to care, rather than reinforcing a rigid and clinical approach.

### **Improve the efficiency of long-term care through actions that increase the use of home care and allow institutional specialization**

There are several ways governments could ease the burden on long-term care institutions and free up financial and staff resources to improve the quality of life of residents.

One way is by increasing the provision of home care services. Among OECD countries that provide data on long-term care provision by sector (home care versus institutional care) and that provide long-term care to a similar proportion of their older population as Canada (13 per cent of people 65 and older),<sup>8</sup> six have a lower share of beneficiaries in institutions: New Zealand, Norway, Germany, Denmark, Switzerland and Israel. Among these six, the average share of beneficiaries who are in institutions is 23 per cent, versus 32 per cent in Canada, according to data published by the OECD (n.d.a). If Canada were to reduce the share of long-term care beneficiaries to 23 per cent

and transfer the nine per cent of residents to home care it could potentially save 6.75 per cent of the total budget spent on long-term care (assuming that home care costs 25 per cent the amount of resources needed for a resident, and nine per cent of residents could have their care needs met through home care.)<sup>9</sup>

Governments will also need to address barriers to home

#### **Barriers to Home-Care:**

- 1. Difficulty navigating the health system**
- 2. Financial barriers (particularly for rural and remote areas)**
- 3. Responsiveness in terms of the reliability of home care services**
- 4. Access to special services such as social or cultural needs**

<sup>8</sup> We focus on countries that cover at least the same proportion of the people 65 and older because we don't want to argue for a reduction in overall coverage and generosity.

<sup>9</sup> We arrive at this share as follows: total expenditures on institutions in Canada represents 1.3 per cent of GDP, whereas total expenditures on long-term care is two per cent of GDP. Therefore, facilities represent 65 per cent of the cost of long-term care. Since 32 per cent of beneficiaries are in facilities, this implies that, on average, a bed in a facility costs four times as much as a bed in home care. Of course, this higher cost results from the higher need on average of those who are living in residential care compared to those in the community. Our assumption here is that nine per cent of residents are in lower need and could live in the community.

care that are leading people to choose institutional care. A 2020 study by the Canadian Institute for Health Information (CIHI) found that one-in-nine residents (11 per cent) admitted to long-term care institutions could have potentially been cared for at home (CIHI, 2020b). It identified four barriers to home care among the residents: difficulty navigating the health system; financial barriers (particularly for those in rural and remote areas); responsiveness in terms of the reliability of home care services; and access to special services such as social or cultural needs.

A six to seven per cent reduction in costs is not huge, but it could ease budget constraints enough to help facilities invest in quality of life improvements (e.g., smaller facilities or more flexibility in the allocation of caregivers' time). It is also possible that the percentage of residents who could be cared for in the community is higher than our estimate. According to CIHI, about one-in-five seniors in their sample data who entered long-term care had similar needs to those supported in the community. Seniors assessed in a hospital versus a community setting are 8.7 times more likely to be admitted to long-term care institutions if they have moderate priority care needs and 3.5 times more likely if they have high priority care needs. Within this sample data, admission to long-term care could have been delayed or avoided for a further subpopulation of individuals with appropriate community-based supports, altering the ratio to one in three (CIHI, 2017).

Governments could also improve system efficiency by dedicating more long-term care institutions to a particular set of needs, such as cognitive impairment (e.g., Alzheimer's disease and dementia). A more homogeneous resident population would make it easier to focus human and financial resources on the common needs of residents. It may also make it easier to determine the right institutional balance between preventing death and supporting quality of life.

Family members are another important resource to improve resident care. The ban on visits from family members during the early days of the pandemic highlighted the prominent role family members play in the provision of long-term care. More effort could be made to integrate family members (or friends and volunteers) into long-term care systems in order to enhance the quality of life of residents.

### **Estimate costs associated with long-term care in the coming decades, and identify mechanisms to finance those costs**

We need to have a serious discussion about how much we – as Canadians – are willing to spend on long-term care, recognizing that many of us will require care at some point in our lives. Quality comes at a cost. It requires more human and financial resources, and it may also require smaller and more personalized facilities. Part of that discussion will need to be about the share of costs that should be borne by governments versus individuals and their families.

A report by the Office of the Parliamentary Budget Officer (Segel-Brown et al., 2021), estimates the costs of improving long-term care at an additional \$13.7 billion per year based on a motion tabled in the House of Commons by Paul Manly, a former Green Party MP



**Table 5. PBO report estimates it will cost \$13.7 billion a year to reform LTC***Estimated cost of selected proposals for long-term care reform*

House of Commons motion proposals	PBO cost estimate
Providing long-term care to all persons who need it	\$3.1 billion/year
Increasing the average pay of all long-term care staff to match public sector pay	\$1.1 billion/year
Requiring an average of four hours of care per resident	\$4.3 billion/year
Increasing spending on home care to 35 per cent of public spending on long-term care <sup>1</sup>	\$5.2 billion/year
<b>Total</b>	<b>\$13.7 billion/year</b>

Source: Segel-Brown et al. (2021).

Note: <sup>1</sup>This is estimated within the context of increased spending for institutional care (\$8.5 billion added to the existing \$20 billion), which would require home care spending to increase by \$5.2 billion to equal 35 per cent of total long-term care expenditure.

(see table 5). This would represent a doubling of current public spending on LTC, and the PBO predicts costs would grow by around 4.1 per cent per year thereafter.

These estimates don't include the full costs of the staff and facilities that would be required to improve the psychological and social well-being of long-term care residents. To provide social or emotion-based care, staff would have to spend more time with residents, or, rather, would have to spend as much time as needed on a specific interaction. This will require more staff hours, increasing costs. Ontario's *Fixing Long-Term Care Act*, introduced in 2021, aims to increase the average amount of time of care spent with each resident to four hours-per-resident a day, which is an important step in the right direction. However, emotion-based care might require much more than that on some occasions, and less so on others. Emotion-centred care is less standardized than clinical care and requires more staff on average and less emphasis on "efficient" use of time. It might be the same on average, but it is not as easy to monitor as the type of medically oriented care that is currently provided.

Emotion-centred and social care might also require a less efficient use of space. Most facilities in Canada are large; for example, the average facility in Ontario has 124 beds (OLTCA, n.d.). The justification for large facilities is economies of scale: some resources (kitchen, heating) represent fixed costs and cost less per resident if used by more residents. But large facilities can over-stimulate residents and lead to a sense of being lost (Chaudhury et al., 2018). Downsizing facilities can improve residents' quality of life. There is no definitive empirical answer on the cost of reducing the size of facilities. However, smaller facilities will cost more per resident.

One financial tool that could help increase the share of home care in Canada could be a form of long-term care insurance. A 2022 study of cost-saving opportunities in long-term care in Quebec proposed a "senior's care account" that would allow individuals to purchase services from both home and institutional care providers (Clavet et al., 2022).



A study by Flood et al. (2021) found that cash-for-care benefits, which provide direct public transfers to LTC residents or their caregivers, could hold promise as a means of enhancing home care in Canada.

Today, Canadians in most provinces face extremely rationed home care services. Many have to pay for home care with their own money or be institutionalized in order to benefit from public support. If we gave individuals financial support to access home care, fewer would be forced to be institutionalized and could remain in the community.

## CONCLUSION

Navigating the post-pandemic period of reflection on long-term care won't be easy.

The pandemic revealed a series of underlying challenges associated with institutional long-term care that go far beyond preventing deaths from infectious disease. If governments learn the wrong lessons from the experience and enforce a rigid and highly monitored form of institutional care based solely on preventing death, Canada's elderly will face a future with a lower quality of life.

Instead, governments should use the experience to create a better model of care that focuses on the needs and interests of recipients. A resident-centred model may require a looser form of guidance for institutions – one that provides greater flexibility and places less reliance on preventing mortality or hospitalization. It will also require more human and financial resources. Improving the efficiency of the system, through greater use of home care and more specialized institutions, could help alleviate some of the pressure. Ultimately, Canadians will need to have a broader conversation about how much we as a society are willing to pay to provide quality care, and how these costs should be shared between individuals and governments.

With Canada's rapidly aging population, it is more critical than ever that governments map out a path forward for long-term care.

## APPENDIX A

### Methodology: Ratios of observed to expected number of deaths in Canadian LTC institutions

#### Outline of method:

Building upon Fisman et al. (2020), we use age-specific mortality rates to calculate an expected number of deaths:

- **Step 1:** We apply the COVID-19 mortality risk (number of deaths due to COVID-19 per 100,000 persons) for the first half of 2020 of the Canadian population to the population of residents in LTC homes in 2018. This gives us an expected number of deaths due to COVID-19 in LTC homes if the institutions had the same mortality risk as the total population.
- **Step 2:** We calculate the ratio of the observed number of deaths due to COVID-19 for the first half of 2020 to the expected number estimated in Step 1. This ratio is the differential mortality in LTC homes due to COVID-19 during the pandemic's first wave.
- **Step 3:** We apply the all-cause mortality risk (number of deaths of all causes per 100,000 persons) for 2018 of the Canadian population to the population of residents in LTC homes in 2018. This gives us an expected number of deaths due to all causes in LTC homes if the institutions had the same all-cause mortality risk as the total population.
- **Step 4:** We calculate the ratio of the observed number of deaths due to all causes in 2018 to the expected number estimated in Step 3. This ratio is the differential mortality in LTC homes in a nonpandemic year.
- **Step 5:** We take the ratio of the ratios calculated in Steps 2 and 4, which gives us the excess in differential mortality in LTC homes during COVID-19 compared to a nonpandemic year.

The population of residents is the population that has been in an LTC home during the period (here, the fiscal year 2018-19, April 2018 to March 2019). It therefore includes those who have been present all year long, plus those who have been admitted during the year and those who have been discharged during the year.

We don't have the same age categories for the population in LTC homes and the mortality risks (all causes or COVID-19). Because of that, we need to estimate the number of residents of LTC homes in the age categories used by Statistics Canada to calculate the mortality risk. We do this by linear interpolation (see below).

We don't have the population of LTC residents for Canada, but only for some jurisdictions. Our expected numbers are estimated on this subset of residents. As a result, we need to extrapolate. To do this, we use statistics on the total number of residents in Canada (not the subset of jurisdictions included in our age distribution). There are different numbers to choose from, including 285,000 residents (CIHI), 425,000 residents including those living in retirement homes (OECD), 298,000 (PBO) and 329,000

(OECD, excluding those in retirement homes). We could disregard the 425,000 that includes those living in retirement homes. Results are robust to the extrapolation, with ratio of ratios in Step 5 comprising between 2.2 and 2.5 (if we exclude the sensitivity analysis at 425,000, which yields a ratio of ratios of 2.0).

### Details on the interpolation and the extrapolation

**Interpolation:** Published data on the age distribution of residents of LTC homes use the following age bands: [0-64], [65-74], [75-84], [85-94] and [95 and older]; published data on mortality risk due to COVID-19 or all-causes in the population use the following age bands: [0-19], [20-29], [30-39], [40-49], [50-59], [60-69], [70-79] and [80 and older]. We need to reconstitute an age distribution of residents in the following age bands: [0-59], [60-69], [70-79], [80 and older]. To do this, we redistribute the numbers in the LTC home age bands into the mortality risk age bands; for instance, we need to decide how many of those in the [65-74] age band belong in the [65-69] band and how many in the [70-74] band. An easy approach would be to allocate half to each, but that would generate discrete jumps in the distribution that don't seem to be realistic. This is why we opted for a linear interpolation: for each age band after [0-64], we calculated the mid-point age of the band (e.g., 69.5 for the band [65-74]) and we estimated a linear regression of the number in each band on the mid-point age of the band (this is a regression on four data points). Note that we assumed that the representative age of the last age band [95 and older] was 97. We then used the estimated coefficients to predict the numbers in the sub-bands. Once we have the numbers for these five-year age bands, we simply add them to get the numbers for the 10-year age bands of the mortality risk: for example, having estimated the numbers of LTC residents in the age bands [70-74] and [75-79], we get the number of LTC residents in the age band [70-79]. This works for age bands after [0-64]. To distribute the number of residents between [0-59] and [60-64], we use some supplementary information in the published data, namely the average age of the population of residents. Assuming that the average age in each band is the mid age (e.g., 67 for [65-69], and 97 for [95 and older]), we can calibrate the average age of the first band [0-64] by picking the value that will yield the grand average age. Once we have the average age of the youngest category,  $x$ , we can calculate the proportion  $p$  in the sub-band [60-64] using the following formula:

$$p = \frac{x - 30}{62 - 30}.$$

The average age  $x$  in the [60-64] band is calculated as follows:  $x = p \cdot 62 + (1 - p) \cdot 30$ , where 30 is the assumed average age in the sub-band [0-59] and 62 is the assumed average age in the sub-band [60-64].

**Extrapolation:** The numbers we have for the population of residents are known only for a subset of jurisdictions (Newfoundland-Labrador, Ontario, Manitoba, Saskatchewan, Alberta, British Columbia and Yukon). We need to use our distribution (proportions of the population of residents in each age band) and apply it to some measure of the total number of residents in LTC homes in Canada to get the age distribution of residents in Canada (the numbers to which we apply the age-specific mortality risks for COVID-19 and for all causes). We found two such statistics: one from the OECD (n.d.b), which included 329,000

residents treated in a year (including discharges and admissions as well as residents present the whole year); and another included 425,000 (Clarke, 2021). The latter number includes residents of retirement homes, which is likely out of the scope of mortality data published for LTC homes in 2020. The former number seems more in line with what we are interested in measuring. We can also use two more recent statistics published; one by CIHI (CCRS quick stats 2018-19) and the other by the PBO (Segel-Brown et al., 2021). These are a count of the number of beds. One bed accommodates more than one resident during any given year, due to discharges (mostly deaths) and admissions. Data from the Continuing Care Reporting System quick stats 2018-19 provide the number of residents, number of admissions and number of discharges during the fiscal year. Assuming a 100 per cent occupancy rate at any time during the year, we can use these numbers to calculate a ratio of residents per bed (how many residents occupy the same bed sequentially during the year) as follows:

$$\frac{R}{B} = \frac{R}{(R - \frac{A+D}{2})}$$

where  $R$  is the number of residents (known quantity),  $A$  is the number of admissions (known quantity),  $D$  is the number of discharges (known quantity) and  $B$  is the number of beds (unknown). We use the average number of  $A$  and  $D$  because, even though these numbers are very similar,  $A$  tends to be slightly greater than  $D$  (some beds are opened during the year). It is therefore a convenient approximation. Using that ratio, we can use the number of beds to calculate the number of residents. We find 286,000 residents using the CIHI number of beds, and 296,000 using the PBO number of beds. We consider the range 286,000 to 329,000 to be a credible number of residents in LTC homes in Canada in the period of interest.

### Second interpolation of mortality risks (five-year age bands instead of 10-year age bands)

For each 10-year age band, we take the mid age (e.g., 4.5 for 0-9) and we regress the mortality risk on these mid ages and the squared value of mid age. We then use the coefficients to predict the mortality risk of a five-year age band using its mid-age value and their squares (e.g, two and four for 0-4 and seven and 49 for 5-9). This allows us to generate a parabolic link between age and mortality risk that is more fine-grained and reflects better increased mortality at very old ages than the 10-year age band mortality risks.

### Observed number of deaths

For the number of deaths due to COVID-19 in institutions, we use data published by the federal government. Perhaps surprisingly, the number of deaths of residents of institutions due to all causes for the nonpandemic year was not recorded or, at least not published, and we had to estimate it (infer it) based on data on the number of discharges (CIHI, 2019). We assume that every discharge from an institution is a death, meaning that no resident can be discharged for any other reason. This is an approximation, but it does not seem inaccurate (personal communication during Centre for Health Economics and Policy Analysis seminar). We then use the extrapolation factors described above to get the total number of deaths in Canadian institutions.

## APPENDIX B

### Standardizing by health status

It is well known that residents are more likely to suffer from illnesses such as diabetes or cardiovascular diseases that also increase the case fatality of COVID-19 (Auditor General of Ontario, 2021). We chose not to standardize based on this due to a lack of reliable data to run the full standardization.

As a result, our calculated relative risk is a composite of the risk associated with the diseases residents suffer from and of the risk associated with having many individuals in a confined space (as illustrated in the case of flu outbreaks in institutions by Lansbury et al. 2017). The former risk is not something that institutions can do much about; the latter is partly a constraint (institutions cannot do much about it) and partly the result of what institutions do to prevent the spread of infectious diseases. Again, ideally, we would want to decompose the relative risk into three components (that associated with the health profile of residents, that associated with the fact of having many individuals living in a confined space and that associated with interventions institutions can implement but did not), but we can only suggest a crude decomposition between health profile and the rest given the paucity of data.

To understand the effect of the conditions of residents on mortality, we use data on COVID-19 case fatality among individuals suffering from various conditions, including CVD, respiratory, diabetes, hypertension and dementia (World Health Organization, 2020, except dementia, which comes from an odds-ratio in the systematic review [Zuin et al., 2021] and authors' calculations) combined with data on the prevalence of these conditions in institutions (Auditor General of Ontario, 2021) and in the community (Public Health Agency of Canada, Canadian Chronic Diseases Surveillance System, <https://health-infobase.canada.ca/ccdss/Index>; it provides prevalence rates for the 65-79 years old and the 80+ and we weighted these prevalence rates by the proportions of the same age groups in the population of residents of institutions).

We run crude simulations for two categories of conditions only (CVD and dementia) as these are the only ones for which prevalence in institutions is significantly higher than in the community (Auditor General of Ontario, 2021; Zuin et al., 2021; PHAC, CCDSS; WHO, 2019). We make the simplifying assumption that the effect of CVD is that of 0.759 residents with CVD and the complement to one with no condition at all (and, similarly, 0.343 community dwellers with CVD and 0.657 with no condition at all). The relative frailty of residents of institutions thus measured would yield a 1.9 over-mortality due to COVID-19 in institutions. This, certainly, is an underestimate of the true effect, since residents are frail not only due to being more likely to suffer from CVD or dementia, but also both at the same time. We don't know what the case fatality is when someone suffers from combined dementia and CVD and cannot as a result run the simulation.

## APPENDIX C

### Note regarding methodology

The issues we raised about published data on Canadian LTC institutions also apply to other types of data. Specifically, Statistics Canada conducts an annual survey of institutions, and data from this survey would allow researchers to create their own tabulations, using consistent age categories and extracting relevant information at the national level on discharges or the age distribution of the resident population. However, and for reasons not provided, the individual-level data from that survey are not made available to researchers, even though the secure network of Research Data Centres run by Statistics Canada on university campuses. Business survey data are as a rule less accessible than household survey data, which is somewhat understandable. It is still unfortunate that institutions benefit from total opacity and that their financial and demographic data cannot be analyzed by the scientific community.

## GLOSSARY

**Community:** This is the term used in the literature on long-term care to name the location of those who are not institutionalized. An individual can either live in the community (in private housing) or in an institution (in a collective household). In the paper, we use “institutional care sector” for care delivered to dependent individuals in institutions and “home care sector” for care delivered to dependent individuals in the community.

**Differential mortality in institutions:** We define it as the ratio of mortality in institutions to mortality in the community. If the ratio is greater than one, it indicates that individuals living in institutions are more likely to die than individuals living in the community. As much as possible, we compare age-standardized mortality in the two settings, to account for the fact that individuals in institutions are older than individuals living in the community.

**Emotional care:** Care that addresses psychological or ontological needs (dignity of the human being) rather than physical or biological needs. A patient who receives the best, state-of-the-art medical treatment without being shown attention to pain or stress, or without being asked to share and understand the decisions in their treatment is deprived of emotional care. To provide emotional care requires spending time listening to the resident/patient and respecting their agency, which can sometimes lead to seemingly inefficient processes.

**Home care:** Care delivered to dependent individuals living in the community and in relation to their dependence.

**Institutional care:** Care delivered to dependent individuals in institutions.

**Institutions:** Facilities where dependent individuals live. These individuals can be of any age. We focus on elderly dependent individuals living in institutions. Other terms, such as nursing homes or long-term care institutions are also used in the literature. We prefer institutions because it is more neutral than nursing homes and also because long-term care, in our perspective, encompasses home care (received in the community) as well as institutional care (received in an institution). We fully appreciate that the term “institution” is restrictive and does not represent the type of care that would ideally be provided. However, it remains the case that the type of care provided in these facilities can be called institutional and has not yet moved toward a more social model focusing on a homelike environment and quality of life.

**Long-term care:** We use the term long-term care for care provided to dependent individuals whether they live in the community or in an institution. It is often used in the literature in a narrower sense to signify care provided in institutions only, but, in this paper, we use the term institutional care to cover that type of care.

**Mortality (or mortality rate):** This is the number of deaths in a population divided by the population size (it is therefore a rate).

**Proportion of COVID-19 related deaths in institutions:** This is the ratio of the number of deaths due to COVID-19 that took place in institutions to the total number of deaths due to the virus in the province (deaths that took place in the community plus deaths that took place in institutions).

**Quality of life:** This is often defined in complement to quantity of life (number of years lived). It can be health-related quality of life, meaning that years of life are valued depending on functional limitations or symptoms of illnesses (a year of life with reduced mobility may be considered to have less quality than a year of life with full mobility in some circumstances). But it can also be closer to well-being or satisfaction, independent of their objective situation (functional limitations or diseases). Quality of life often requires emotional care.



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