

Rights versus Risks: The Impact of Isolation on Residents and Families in Long-Term Care

Les droits contre les risques : l'impact de l'isolement sur les résidents et les familles dans les établissements de soins de longue durée



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Abstract

Early in the COVID-19 pandemic, the Ontario government created directives for long-term care (LTC) homes. As a result, residents were isolated in their rooms and visitors were banned. This commentary examines these practices and their impact on LTC residents and their families. A review of relevant documents showed the practices were unnecessary and physically and psychologically detrimental. Moving forward, family should be recognized as essential members of residents' care teams and allowed in LTC homes during outbreaks. This would entail providing them with the necessary protective equipment and adequate training to ensure infection prevention protocols are maintained.

Résumé

Au début de la pandémie de COVID-19, le gouvernement de l'Ontario a élaboré des directives pour les foyers de soins de longue durée (SLD). En conséquence, les résidents ont été isolés dans leurs chambres et les visites ont été interdites. Le présent commentaire examine

ces pratiques et leur impact sur les résidents des SLD et leurs familles. Un examen des documents pertinents a montré que ces pratiques étaient inutiles et préjudiciables tant sur le plan physique que psychologique. Dorénavant, la famille devrait être reconnue comme un membre essentiel des équipes de soins et elle devrait être autorisée dans les foyers de SLD pendant les éclosions. Cela impliquerait de leur fournir l'équipement de protection nécessaire et une formation adéquate pour garantir le maintien des protocoles de prévention des infections.

Background

The long-term care (LTC) sector in Canada was ravaged by COVID-19. As of January 15, 2021, residents of LTC homes accounted for almost 60% of pandemic-related deaths in Ontario (Government of Ontario 2021). The Long-Term Care COVID-19 Commission found the province had “no comprehensive plan to address a pandemic. Worse yet, there was no plan to protect residents in long-term care” (Marrocco et al. 2021: 2). A convergence of evidence shows the provincial government was warned regarding “the looming dangers lurking in long-term care homes ... [but] failed to deliver what was desperately needed” (Russell et al. 2021: 6).

Ontario has the largest population nationwide, followed by Quebec and British Columbia. In comparing the three provinces, Quebec was the first to restrict LTC home visitation to essential visitors and Ontario was the last (Lysyk 2021). British Columbia was the first to mandate home staff wear masks and refrain from working in more than one LTC home. Ontario did not implement these measures until more than a month later (Lysyk 2021).

British Columbia led the country in demonstrating “best practices around health communication” pertaining to COVID-19 (Zussman 2020). In Ontario, however, LTC homes and the public received mixed messages from the Ministry of Long-Term Care and the Chief Medical Officer of Health (Lysyk 2021). This lack of comprehensive, consistent communication created significant confusion, which exacerbated the impact of Ontario government directives that prohibited visitors from entering LTC homes, restricted residents' movements and led to extended periods of isolation. This article is a commentary that examines one province's social isolation policies and practices and their effect on LTC residents and their families. Relevant documents were reviewed and included legislation, directives, newspaper reports and policies.

What relevant legislation was invoked during COVID-19?

On March 17, 2020, the Government of Ontario (O. Reg 50/20) declared a state of emergency in response to COVID-19. The *Emergency Management and Civil Protection Act (EMPCA)* (1990) allowed the Lieutenant Governor in Council to issue orders, under section 7.0.1(1) of the EMPCA, believed “necessary and essential in the circumstances to prevent, reduce or mitigate serious harm to persons or substantial damage to property” (EMPCA 1990).

The *Health Promotions and Protection Act (HPPA)* (1990) establishes the framework under which directives may be issued to LTC homes. Under section 77.7(1) of the *HPPA*, Ontario's Chief Medical Officer of Health is empowered with discretion to issue orders to healthcare providers, including LTC homes, with respect to precautions and procedures to protect the health of persons in Ontario if they are of the opinion that there is, or may be, an immediate risk (*HPPA* 1990). Directive #3, specific to LTC, was issued under the *HPPA* to govern visitor restrictions, isolation requirements and short-stay absences; define non-essential visitors; and cohort staff and residents (MLTC 2020). Eleven versions of Directive #3 were released between March 22, 2020, and December 7, 2020 (AdvantAge Ontario 2022).¹

DIRECTIVE #3

The first version focused on limiting short-stay absences for LTC residents but allowed outdoor visits with family to continue. As per the second version, LTC homes continued to bar short-stay absences and outdoor visits with family were removed. Additionally, no visitors were allowed to enter the home with the exception of an essential visitor defined as “a person performing essential support services (e.g., food delivery, maintenance and other healthcare) or a person visiting a very ill or palliative resident” (MLTC 2020: 4). Resident and staff cohorting measures were issued and included isolating residents to their rooms if there was an outbreak or if the resident was a new admission. There was a stipulation included that “in smaller long-term care homes or in homes where it is not possible to maintain physical distancing of staff or residents from each other, all residents or staff should be managed as if they are potentially infected” (MLTC 2020: 4). The third version continued the restriction on visitation but further modified the definition of essential visitors to include support services such as laboratory and food. It was not until the fourth version that family members were included under the definition of essential visitors. No changes were made to resident and staff cohorting in the third, fourth, fifth or sixth versions.

It was not until the seventh version (June 11, 2020) that homes were instructed to develop the gradual resumption of visitor policies that included family members, beginning with one visitor at a time. The eighth version allowed residents temporary absences for personal reasons with 14 days of self-isolation upon their return. The ninth version made no changes to cohorting or isolation practices but allowed residents to receive a maximum of two visitors at a time. Homes had discretion to impose additional rules such as requiring visits to be scheduled in advance and limiting the duration of visits. The 10th and 11th versions maintained the same precautions and procedures as the ninth version in relation to cohorting, isolation and visitation.

How did isolation and visitor restrictions affect residents and families?

Isolation of LTC residents in Ontario and restrictions on their movements persisted from April 1, 2020, to June 11, 2020, despite scientific evidence demonstrating that “extreme isolation is physically and mentally damaging” and it was known that COVID-19 would be “far

less likely to spread outdoors than indoors” (Perkel 2021). Evidence also demonstrates that a lack of physical activity exacerbates existing medical conditions, including diabetes and osteoporosis, and adversely affects mental health (McPhee et al. 2016). In addition, factors such as lack of sunlight and movement contribute to vitamin D deficiency, muscle atrophy and reduced strength, which can increase the threat of falls and fractures for older persons (DiPietro et al. 2018; Leonard 2020).

Due to rigid adherence to the broad and continual application of these isolation measures, many residents lost vital connections with their family caregivers and the world outside the LTC home. In some cases, residents lost their substitute decision makers. It is common practice for residents to appoint someone to act as their advocate and help them to understand their situation and make appropriate decisions. Directive #3 prevented residents from having in-person consultations with their substitute decision makers, which severely hampered their ability to provide informed consent, diminished their agency and increased their vulnerability. It also hampered the ability of substitute decision makers to fulfill their duties as outlined in the *Substitute Decisions Act, 1992* (Ontario Ministry of the Attorney General 2020) and the *Health Care Consent Act (1996)*. The use of tablets and smartphones facilitated communication but excluded those residents who lacked the necessary understanding, aptitude and senses (hearing and vision).

A review of newspaper reports shows how prolonged isolation affected LTC residents and their family members (see Table 1).

TABLE 1. Newspaper reports of the impact of isolation on residents and their family members

Outcome	Source	Comments
Depression and immobility	<i>Toronto Star</i> – July 2020	"In isolation [my dad] got tired of being told to go back into his room so he decided to just stay there. When they tried to get him on his feet again, he would roll over in bed and refuse to speak." ^a
Severe weight loss and unresponsiveness	<i>CBC News</i> – October 2020	"When we first saw her [during a window visit], she was in such terrible condition. She had lost 30 pounds. She was unresponsive." ^b
Distress	<i>Toronto Star</i> – October 2020	"Being alone in one room every day almost made me crazy." ^c
Loss of function and overall strength	<i>The Globe and Mail</i> – August 3, 2020	"After a series of medical crises and isolation stemming from the COVID-19 pandemic, the Toronto-area couple's health has deteriorated so dramatically [that] they need round-the-clock care." ^d

^a Welsh 2020a.

^b Roumeliotis and Mancini 2020.

^c Welsh 2020b.

^d Mahoney 2020.

These findings were corroborated by the review of key policy documents, specifically the Canadian Armed Forces Joint Task Force (Central) report (CAF JTFC 2020), Ontario's Long-Term Care COVID-19 Commission report (Marrocco et al. 2021) and the Royal Society of Canada policy briefing (Estabrooks et al. 2020). The Joint Task Force recounted egregious incidents of residents "crying for help with staff not responding for 30 minutes to over 2 hours," feeling fearful and abandoned "like they're in jail," being denied adequate nutrition and not receiving "psychosocial support ... [after having] their families taken away" (CAF JTFC 2020: 5, 9, 12). The Long-Term Care Commission noted the "isolation, fear ... [and] sorrow" experienced by LTC residents and the "deteriorating levels of ... care and quality of life visited upon residents" and their families (Marrocco et al. 2021: 239, 312). The Royal Society likewise acknowledged the "high levels of physical, mental and emotional suffering" endured by LTC residents (Estabrooks et al. 2020: 30).

Whose rights were violated?

LTC residents' rights are enshrined in legislation under the Residents' Bill of Rights, *Long-Term Care Homes Act, 2007*. The legislation is clear that the 27 enumerated rights are to be fully respected and promoted. This includes the right to be cared for, the right to fully participate in decision making regarding care, the right to receive visitors and the right to consult with any person without interference.

Directive #3, which excluded family caregivers from homes for lengthy periods and resulted in residents isolated to their rooms even when they were not symptomatic or at risk, was a breach of residents' rights under this legislation. Residents could argue it violated their right to life based on evidence that the loss of supplementary caregiving resulted in a deterioration of their health that was sufficiently connected to an increased risk of death. Residents may further be able to argue that the inability to access their substitute decision maker in person or obtain the support of family caregivers in understanding medical decisions was a deprivation of their right to liberty and security of person. They may also be able to assert that preventing their access to essential caregivers resulted in physical and psychological suffering and harm and permanent damage to their level of independence and functioning.

What could have been done differently?

Studies, newspaper reports and policy documents highlight the consequences of isolation and visitor restrictions. Internationally, researchers have found "lockdown causes risks of cognitive decline, depression, anxiety, frailty and disabilities" for nursing home residents (Pitkälä 2020: 889), while barred "visitors experienced low psychosocial and emotional well-being" (O'Caomh et al. 2020: 2). Researchers in Australia determined "there are risks for those families living with chronic stress and social isolation" due to COVID-19 (Deakin University 2020).

An ethical analysis conducted in the US showed how "the risk of harm secondary to isolation increased over the time that the restrictions remained in effect" (Purvis Lively 2021: 1).

This harm included the heightened potential for adverse events and outcomes such as functional, cognitive and physical decline (National Academies of Sciences, Engineering, and Medicine et al. 2022). In addition to supplementing care, family members monitor for signs of abuse and neglect. An integrative review of the effects of visiting restrictions in various countries concluded:

From a caring perspective, family members can be seen as external partners or an essential and internal part of a patient’s care team. (Hugelius et al. 2021: 8).

According to Coulter and Richards, a “humane approach to visiting policies in hospitals and care homes need not be incompatible with an effective pandemic response” (2020: 1). We contend that such an approach is not only humane but also progressive as it supports collaboration between family members and healthcare staff. Drury et al. (2020) have observed:

In our rush to contain COVID-19, we have both minimized and mischaracterized the essential role family and caregivers of patients with complex needs serve as the backbone of the health system. Without them playing an active role in care, the fact is there will be an unmanageable additional burden on healthcare providers tackling COVID-19.

When family members participate in the provision of care, it frees up staff to focus on other residents. This is particularly important in sectors with understaffing and low surge capacity such as LTC (Andrew-Gee and Stone 2020; Baumann et al. 2006).

It is reasonable to assume that family members understand that care includes various practices to safeguard their loved ones and are used to taking the necessary precautions such as not visiting when feeling ill and appropriately using personal protective equipment. Rather than applying and adhering to blanket policies restricting their access, LTC homes could have provided them with infection prevention and control (IPAC) education and training specific to COVID-19 and permitted visits to continue. The International Long Term Care Policy Network found that allowing “family caregivers [who are] using safe visiting practices does not lead to COVID-19 infections when community transmission levels are low” (Low et al. 2021: 3). In Ontario, it was only late in Wave 1 of the pandemic that one family member per LTC resident was allowed to enter a home under the essential visitor category. One home reportedly counted a paid personal support worker as an essential caregiver thereby reducing the number of family members to visit. Consequently, many homes neglected to tap an important resource early on – one that could have improved outcomes for residents and kept vital connections intact.

Cross-provincial approaches

In contrast to Ontario, LTC homes in other provinces developed and implemented various

successful strategies to maintain in-person family visits. In New Brunswick and Manitoba, multiple homes used family members as volunteers and provided them with advanced IPAC training. In a national webinar on November 29, 2020, it was noted that there was no increase in COVID-19 due to this strategy (Healthcare Excellence Canada 2021). To contain the spread of infection and reduce social isolation, a home in Nova Scotia capitalized on its unique physical design and used a phased approach for on-site family visits. The home features “10 self-contained households with separate entrances and private resident rooms” (Fancey et al. 2021: 15). Family members were provided with information about IPAC and had to demonstrate their understanding of safety protocols and processes related to entering residents’ households. In British Columbia, one home designated physical space as a family visitation centre. Another home hired family caregivers as cleaners to offset a shortage of personnel. Although controversial, this strategy provided family members with access to the home and allowed for family visits at designated times.

Discussion

This commentary demonstrates that decisions made during the pandemic to isolate LTC residents and restrict visitors not only infringed on residents’ legal rights but also negatively affected individuals and their families. Reports, anecdotal evidence and media coverage confirm that family members were denied access to LTC homes even though they met the definition of *essential* as stipulated in government directives. Visitor restrictions severed critical family ties for residents and invalidated the valuable role that families play, while isolation created unnecessary trauma and despair for residents and their families. Various lawsuits filed by family members focus on the conditions in LTC homes and their responses to COVID-19. The lawsuits allege the homes violated the “charter rights to life, liberty and security of person” (Ontario Health Coalition 2020: 4).

If the overall goal of LTC is “to create long-term care home environments where residents feel at home, are treated with respect, and have the supports and services they need for health and well-being” (Government of Ontario 2011: 1), how does a care home reconcile the risk of virus transmission and the consequences of social isolation? Early in the pandemic, many LTC homes in Ontario had no outbreak yet they still banned all non-essential visitors, including family caregivers. According to news reports, care homes asserted they did what was mandated and what was right given the circumstances and government directives. This underscores a significant issue: Just because something is “legal” does not make it ethical.

Several groups, including the Patient Ombudsman, argued for the continuation of visits with the proviso that the number of caregivers should be limited and essential IPAC measures and necessary oversights should be in place. This perspective was ignored. Furthermore, the decision to create an essential visitor category resulted in confusion and frustration due to the ever-shifting definition of essential visitor through various versions of Directive #3. Overall, it was clear that LTC homes had difficulty understanding and developing policies that met residents’ essential caregiving needs.

The subsequent loss of caregiving conducted by family members included critical interventions such as regular bathing, feeding, mobilization, socialization and emotional support. Documents revealed that isolation led to deprivation, decreased function and deterioration of overall health for many LTC residents. Recognizing the unique role of family caregivers and providing them with IPAC training and education would have allowed them to continue visiting and caring for their loved ones and lessened the demands on LTC staff. Moreover, it would have reduced the dramatic and in some cases irreversible effects of isolation. However, this approach was not considered and family members were not given the option.

The decision to isolate LTC residents was an attempt to protect them from infection, but it was made without regard for the significant toll. As early as the 1950s, psychologist Harry Harlow demonstrated the consequences of prolonged social isolation via a series of controversial experiments using animals (Harlow et al. 1965). At the same time, developmental psychologist John Bowlby was interested in understanding the effect of institutional care on orphaned children. Bowlby identified that separation and deprivation were extremely detrimental to young children and their development (van der Horst and van der Veer 2008). His early works revealed that humans require social and physical interventions and interactions to thrive (Bowlby 1952).

Throughout the 20th century, researchers continued to investigate the effects of isolation on the psychological and physical health of individuals. A more recent application of this research can be found in studies that examined the practice of solitary confinement as a form of extreme punishment. Findings from this literature confirm that isolation “can be as clinically distressing as physical torture” (Metzner and Fellner 2010: 104) and secluded inmates endure a range of “harmful effects that vary in severity as they become progressively more anxious, depressed, irritable, confused, aggressive, and suicidal over time” (Luigi et al. 2020: 2).

Similar effects were observed among LTC residents during the pandemic. As per IPAC measures, they were no longer permitted to walk around the hallways, gather in common areas or dine together. They were also forced to isolate in their rooms. Family visits, which were initially allowed by appointment and only for short periods, were eventually barred altogether. Much like segregated inmates, LTC residents had to “live with extensive surveillance and ... the absence of ordinary social interaction ... or other purposeful activities” (Metzner and Fellner 2010: 104). As of March 2021, many LTC residents had been confined to their rooms or floors and denied the companionship of family members and each other for more than a year (Perkel 2021). As the restrictions not only remained but also became even more oppressive, critics began to question the impact of isolation on residents and if their legal rights were being violated.

It took more than 30 years for residents and patients to obtain rights and only weeks to lose them during the pandemic. Moving forward, caregivers should be recognized as essential members of residents’ care teams and allowed in LTC homes during outbreaks. This would entail providing them with the necessary protective equipment and adequate training to ensure IPAC protocols are maintained. The use of private paid caregivers should also be

included, but they should not replace essential caregivers. There has been much said about COVID-19 creating a “new normal.” However, the abrogation of rights in the LTC sector and the restriction of family visitors should never be accepted as normal.

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Note

1. A comprehensive list of all iterations of Directive #3, with links to each version, can be found here: http://www.advantageontario.ca/AAO/Content/Resources/Advantage_Ontario/COVID-19/Ministry_Documents.aspx.

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