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# **#**Morethanavisitor: Experiences of COVID-19 visitor restrictions in Canadian long-term care facilities

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# Abstract

**Objective:** The purpose of this study was to understand the experiences of families, residents, and staff around visitor restriction policies in long-term care during the COVID-19 pandemic in Canada.

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**Background:** Beginning in March 2020, public health orders across Canada restricted visitors to long-term care facilities to curb the spread of the infection. This included family caregivers who provide significant support to residents to meet their physical, psychological, social, and safety needs.

**Method:** We collected data from publicly available news and social media. News articles, blogs, and tweets from Canada were collected from March 2020 to April 2021. In total, 40 news articles, eight blogs, and 23 tweets were analyzed using generic qualitative description.

**Results:** Reports from family members indicate that some residents may have died from malnutrition, dehydration, and isolation, rather than from COVID-19, because of the sudden and prolonged absence of family caregivers. There are long-term impacts on family suffering and long-term care worker burnout. Policy and structural issues were identified.

**Conclusion:** Experiences in long-term care reflected not only impacts of pandemic-related visitor restrictions, but also long-standing funding and workforce issues.

**Implications:** Involvement of family, and specifically family caregivers, is crucial in policy decisions, even in unusual circumstances, such as the pandemic.

#### **KEYWORDS**

COVID-19 pandemic, family nursing, long-term care, visitor restrictions

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The COVID-19 pandemic required public health orders that limited social interactions to reduce spread of the virus. Although decades of policy have informed a movement toward family-centered care in healthcare and recognition of family caregivers, the pandemic-induced limitations meant severe restrictions of visitors to long-term care (LTC) facilities, including family members. The limitations on visitation ultimately had negative consequences for the physical and psychosocial health and well-being of both residents and family members (O'Caoimh et al., 2020). As well, LTC workers experienced hardship because of how their work changed with reduced family access and involvement, staffing issues, and the effects of social isolation on residents and families. Although issues in LTC, interest in family-centered care, and responses to the pandemic have been highly unified globally, this article reports the findings of qualitative media analysis research that investigated experiences of residents of LTC facilities in Canada and their family members, as well as exploring LTC workers' perspectives, during this time. Documenting these perspectives and sharing this analysis will contribute knowledge on the role and importance of family involvement and support, not only in the pandemic, but as we recover and look toward improving LTC in the future.

#### **BACKGROUND AND LITERATURE REVIEW**

For several decades, the patient- and family centered-care movement has been expanding from its initial start in pediatrics into adult populations, across all sectors of healthcare (Barken & Lowndes, 2018; Institute for Patient- and Family-Centered Care [IPFCC], 2022). It is widely recognized that families are not only important to the health and well-being of patients but also should be considered part of the focus of care, including them in decision-making and promoting their health and well-being (IPFCC, 2022; Shamon, 2021; Tupper et al., 2020).

Long-term care facilities are institutions that provide accommodation, healthcare, and personal care assistance for people with moderate to severe long-term dependency; other common names include residential care facilities, aged care facilities, or nursing homes (OECD, 2021). Canadian LTC homes are also called continuing care facilities; LTC residents receive 24-hour nursing care, personal care, and other services (Canadian Institute for Health Information, 2021). In Canada, 2.64% of people over the age of 65 live in an LTC facility (Statistics Canada, 2017a; Statistics Canada, 2017b). Long-term care residents in Canada tend to be older than in other OECD countries; 91% are over the age of 65 and 74% are over 80 years of age (Canadian Institute for Health Information, 2020). This study, therefore, focuses mostly on these older adults.

The family caregiver role in LTC is considered by the Canadian Geriatric Society to be an essential service, and prior to COVID-19 was part of standard care (Tupper et al., 2020). The diverse role of family in LTC settings has been found to include up to 10 hours per week of personal care such as grooming, feeding, hygiene, social and emotional support, mobilization, and advocacy (Barken & Lowndes, 2018; Tupper et al., 2020). Family members act as surrogate decision-makers, care coordinators, advocates, care providers, and an important source of social and emotional support (Hado & Feinberg, 2020). As a specific example, malnutrition affects many LTC residents (Trinca et al., 2020) and family support for feeding in LTC has been shown in research to increase macro- and micronutrient intake at mealtimes (Wu et al., 2020). Social and emotional support from family members mitigates loneliness in LTC residents and helps promote maintenance of baseline cognition (Crooks et al., 2008). Family involvement in care in LTC reduces mortality for residents (Tupper et al., 2020). Current research finds that family members experience grief and guilt when a loved one is transferred to LTC (Barken & Lowndes, 2018, and that there is insufficient psychosocial support provided to family members during this transition (Shamon, 2021). This grief may be further complicated when a family is disabled from attending to the needs of their relative in LTC, particularly if death of the resident occurs during times of limited or restricted contact (Tupper et al., 2020).

Because of COVID-19 visitor restrictions, the risk of malnutrition, immobility, social isolation, and cognitive decline for LTC residents has increased significantly as regular healthcare staff struggle to meet the needs of all residents without the usual family support (Tupper et al., 2020). Much of the direct care and human contact in LTC settings is provided by unregulated care providers; this means many LTC workers do not receive any special education or training to work in this area (OECD, n.d.).

The media has reported many examples of family members and residents being negatively impacted by COVID visiting limitations in LTC, both in Canada and around the world. In our local jurisdiction, for example, the immediate policy response was to restrict all visitors, including family members, except if the resident was thought to be imminently dying (Government of Alberta, 2021). Over time these policies were revised to allow up to two "designated support people" who could enter the facility, after screening and wearing personal protective equipment. These policies, however, varied in implementation between provinces and facilities. When residents and family members are allowed to be physically present with one another, there are limits placed on the amount of physical contact they can have with each other (i.e., they must maintain a physical distance of 2 meters, they must wear a face covering). Residents of LTC may have cognitive and physical impairments (i.e., dementia, hearing or vision impairment) that makes these barriers even more challenging. For example, those who have dementia may not understand why their family member is sitting far away and not holding their hand; those who have hearing impairment may not be able to understand because they depend on proximity and/or reading lips that are hidden behind a mask. Furthermore, residents with cognitive impairments may show reduced recognition of loved ones because of less frequent and limited contact (Tupper et al., 2020).

Resident and family member needs for connection, social support, and touch have likely been severely impacted by the visitation restrictions. Anecdotally, nurses and care providers in these facilities report that limited family visitation has exacerbated challenges with managing resident behavior, created difficulty communicating through personal protective equipment (PPE), and increased reliance on staff to facilitate communication and connection with families, because they also fill in to meet psychosocial needs. For many LTC residents, contact with family members is often a source of emotional comfort and social interaction that is essential to their mental and emotional health and well-being (Taniguchi, 2020). For residents who had no contact with family or friends, 36% experienced moderate to severe depression, compared to 23% of residents who had some contact, including through video or telephone (Canadian Institute for Health Information, 2021). Additionally, as much as 30% of personal care for LTC residents, including help with eating, dressing, and mobilization, is provided by visiting family members (Tupper et al., 2020). The visitor restrictions potentially reduce the physical, social, and emotional care LTC residents receive from family members (CBC News, 2020a). One study examining unbefriended residents in LTC found that healthcare providers (nurses and care aids, specifically) experienced increased stress and burden of responsibility to provide for all needs for this population without family involvement (Chamberlain et al., 2020); it could be extrapolated that the restrictions on family visitation in LTC during the COVID-19 pandemic heighten this experience for employed care providers as each LTC resident becomes as isolated as the others.

Numerous papers have been published on how COVID-19 has impacted residents of LTC, staff, and their family members (see Bergman et al., 2020; Béland & Marier, 2020; Estabrooks et al., 2020; Gray et al., 2021; Tupper et al., 2020; Wammes et al., 2020; Yeh et al., 2020). Internationally, many similar studies over the last 18 months report almost identical ethical tensions, effects, and recommendations for best practices in managing the pandemic, recognizing the important role and impact families have on residents' care and quality of life. Bergman et al. (2020) cite numerous studies that reveal that, "although the [visitor restriction] regulations were deemed essential to COVID-19 containment, the continuation of this lockdown for a prolonged time has resulted in potentially irreversible physical, cognitive, psychological and functional decline" (p. 1760). Inzitari et al. (2020) wrote that these conditions are the same whether in Spain, the Netherlands, Italy, the United States, or Canada:

During the pandemic we have learned that NHs [nursing homes], in their current form and with current resources and priority applied to them (for PPE, testing, medical support), are an unsafe place to remain. In addition, collective decisions, such as the restriction of visitors, have had a major impact on residents and caregivers' quality of life, causing much grief, especially at the end of life. (p. 1044)

The restrictions to family visitation in LTC facilities invoked by the COVID-19 pandemic provide an opportunity to explore the role and importance of families in resident care by examining the impact of their absence on the family members, the residents, and the staff in LTC facilities, as well as the nursing practices that are, or could be, helpful. Our research question was the following: What are the experiences of residents, staff, and families during visitor restrictions in long-term care in response to the COVID-19 pandemic in Canada, as reported in news and social media?

## METHODS

This was a qualitative descriptive study (Kahlke, 2014; Sandelowski, 2000, 2010; Thirsk & Stahlke, 2021). The goal of a descriptive study is the accurate portrayal and summary of participants' experiences (Sandelowski, 2000). This approach enabled us to organize findings thematically and highlight unusual or unique cases. Qualitative research is intended to go beyond self-evident knowledge of a phenomenon, adding insight and new knowledge (Thorne, 2020).

During the pandemic, there has been a reduced capacity to engage these clinical areas in research and it was our desire not to further burden families, residents, or care providers with surveys. Furthermore, there have been reports that nurses and other healthcare workers are reluctant to participate in interviews and surveys on conditions in LTC, out of fear of being reprimanded or fired (Brophy et al., 2021). Thus, the data for this research included media artifacts such as news reports, blogs, and social media postings as representations of stakeholders' experiences. We were granted an ethics exemption by our university research ethics board, as all data were publicly available.

There is a long tradition of researchers using newspaper reports as data in the analysis of social issues and responses to them (Earl et al., 2004). Although newspaper editors can decide which news stories are covered, the type of event and the nature of the issue at hand are strong influencing factors (Earl et al., 2004). The "hard news" of an event, if it is reported, tends to be relatively accurate (Earl et al., 2004). The extreme event type of a global pandemic and the vulnerabilities it produces arguably compel news outlets to cover related stories, producing a significant potential research data set, which is widely available online. Social media, as a unique form of media, including platforms such as Facebook and Twitter, has emerged as a space where users can not only socialize, but also share their experiences, insights, and emotions with others worldwide. Enormous volumes of user-generated content (Snelson, 2016) represents real-world data, which is valuable to researchers seeking to understand health dynamics in global populations. Thus, social media research, particularly research involving qualitative or mixed methods, has increased over the years (Reuter & Kaufhold, 2018; Snelson, 2016). This facilitates a more comprehensive psychosocial understanding of health and disease, in addition to the current pathophysiological understanding (Deng et al., 2020).

## Data collection

The overall search strategy was guided by Snelson (2016) four stage process of pre-searching, searching, data cleaning, and analysis. All items were screened for inclusion criteria; articles were included if they focused on LTC facilities and the COVID-19 pandemic and restrictions on family visitation, within the Canadian context. Any articles not meeting these criteria were

excluded. A library scientist helped design the pre-searching and searching strategies for all potential data sources. The search for news articles was carried out using the library database, Canadian Newsstream, Google (Advanced-News), along with a search of reliable online national news outlets (e.g., globalnews.ca, cbc.ca). Boolean searching included terms such as "long-term care or long term care" AND "visitor restrictions" AND "COVID or coronavirus." To locate blogs from potential participants we used the blog search engines Wordpress, Blogspot, and Blogdigger and the search terms "long-term care," "nursing homes," "family," and "COVID" to locate stories from family members or residents. Using the same search engines, we located stories written by nurses and/or care providers who work in LTC who described their experiences of restricted family visiting.

The Twitter data set was gathered using Postman, an application that allows users to retrieve, test, and document data from Twitter's Application Programming Interfaces (APIs). Initially, Boolean searching was used to identify tweets containing either "COVID OR coronavirus" AND "long-term care OR LTC" (Search 1). However, a second search was run using Boolean searching to identify tweets containing either "COVID OR coronavirus" AND "nursing home OR continuing care" (Search 2). This was done to account for potential differences in terminology. Retweets and replies were excluded to avoid duplications. Furthermore, only tweets geotagged within Canada were included; only 1%–2% of tweets are geotagged (Schlosser et al., 2021). Search 1 yielded 1,125 tweets and Search 2 yielded 265 tweets. Because two separate Twitter searches were run, duplicates were then removed, and tweets were screened for inclusion/exclusion criteria. Tweets that linked to news articles and that did not have other narrative content were included in the news article count below.

Our purposive sample of media artifacts contained articles and social media posts that provided direct quotes, interviews, and/or personal accounts from family members and/or care providers, as well as from policy experts from across Canada. The final sample size was determined as analysis proceeded to ensure sufficient insight and comprehensive understanding (Thirsk & Clark, 2017). Data collection occurred between January 2021 to April 2021 and included data published from March 2020 to April 2021. Our final data set included 40 news articles, eight blog postings, and 23 tweets (Twitter postings), totaling over 250 pages of data, providing a breadth of different perspectives from across Canada.

#### Data analysis

Once the initial sample was collected, data were reviewed by the principal investigator to confirm inclusion/exclusion. Initially, each member of the study team conducted independent content analyses of the media artifacts in which "the many words of the text are classified into much smaller content categories" (Elo & Kyngäs, 2008, p. 109). Following this analytic process, the initial impressions and themes from individual team members were shared during team discussion. This initial analysis was collated, and further refined and expanded by one member of the research team, and then shared back with others in an iterative process, until 100% consensus was reached with the following findings. Rigor was supported through many processes during the research: with systematic searching for data; thorough reading and rereading of data by all authors; documentation of decisions during the data collection and analysis; and consensus building in the final presentation of the results, including direct quotes.

### RESULTS

Data analysis yielded findings that pertain to the experiences of LTC residents, family members, and staff, revealing emotional and physical hardship for all. The data also contained commentary and analysis from policy stakeholders, advocates, and researchers. Themes included resident isolation and family separation and the health consequences associated with the restrictions, the role of family caregivers, the stress of healthcare workers, and structural and policy issues. Because our data set was mainly news articles, citations are provided to indicate the source article for quotes and data excerpts, in the same way that participant numbers or pseudonyms would be indicated after interview quotes. When we use a quote from a resident, family member, staff member, or policy advocate, we indicate this specifically. If this is not stated, the data excerpt is from the journalist's narrative.

#### Isolation, separation, and the health consequences of restrictions

This was the central theme within this data, richly illuminating the impact that LTC visiting restrictions have had on the emotional, and ultimately physical well-being of residents and families. Generally, most LTC homes were very cautious in response to the risks created by the pandemic and were very restrictive about not allowing family in, claiming that the needs of many outweighed the needs of the ones who wanted their family caregivers (Welsh, 2020c, news article). Ontario implemented what has been referred to as an "iron ring" around nursing homes, keeping almost all visitors out (Goldfinger, 2020, para. 20, news article). According to a news report by Bains (2020), the National Institute on Ageing said that families in British Columbia endured the most restrictive visitation policies. The data contain similar reports of restrictions and their consequences from Alberta and Nova Scotia (Bench, 2021, news article; Moore & Jerrett, 2020, news article).

Direct comments from residents were scarce, although what was included from their point of view was profound. Generally, others spoke on their behalf, indicating deep distress and difficulty. In an article focusing on residents' perspectives, Casey (2020, news article) reported on the emotional devastation experienced by LTC residents, who characterized their loss of autonomy as being "muzzled" and "trapped." Casey (2020, news article) quoted one resident who said, "Now when I see these dog cages on TV for stray animals, I see myself as one of these neglected, filthy and starving-for-love-and-affection little critters" (para. 4). A Toronto LTC resident explained:

We are confined basically to our room and our home area. We cannot associate with our peers in other areas of the home. There are no activities as such. We don't go on trips or go out ... now I'm like a bird with its wings clipped. (Fieber, 2020, para. 8, news article)

Profound isolation was evident among residents. One LTC resident expressed that "we are isolated, alone, without family or friends to visit with us... I don't want to go through this ever in my life again" (Casey, 2020, para. 11, news article). Another resident lamented that "the isolation felt like living behind bars, except that prisoners are treated better" (Casey, 2020, para. 14–15, news article). Family members also likened LTC facilities with pandemic restrictions to prison. According to one news report, the daughter of a LTC resident who was unable to visit her mother because of restrictions was pursuing a human rights complaint, arguing that "residents are not prisoners in a pandemic prison, and their rights have been disrespected" (McQuigge, 2020, para. 7, news article). Another daughter shared that her mother expressed how she felt "like a prisoner" in solitary confinement (Mahoney, 2020b, para. 2, news article). A tweet by a physician (May 2020) made note of the isolation experienced by LTC residents:

COVID is isolating our seniors, a vulnerable & [and] often already lonely part of our population. Today an LTC [resident] asked me to hold her. Before lockdown,

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Family Relation

family was in daily to talk, bring her traditional food, & [and] comfort. No longer. So I held her. She was calm.

However, most isolated residents did not have an opportunity for even limited physical contact given the ongoing restrictions. One of the most devastating aspects of visiting restrictions evident in this data was the inability to touch and hug family members. Several of the articles specifically reported on the hardship imposed by the restrictions on physical contact. A tweet from a family member (April 2020) exemplified this hardship, stating: "Today my grandfather 'visited' my Nan through the window of her Halifax nursing home... Seeing my normally stoic grandfather struggle like this just shatters my heart." Another tweet from a family member told how "My dad is in long-term care, my mom isn't. They haven't been able to even hold hands since March. Their 60th anniversary came and went[;] they couldn't even hold hands. Covid 19 sucks."

Even as restrictions eased slightly as the pandemic evolved, family members that were permitted to visit did so with Plexiglas barriers, full physical distancing, and PPE such as gloves, masks, and gowns (Bains, 2020, news article; Welsh, 2020c, news article). These limitations were confusing and distressing for LTC residents who did not understand why their loved ones would not touch them. An Alberta man reported:

[My] mother-in-law was an avid reader and then when she had dementia, and lost her sight, basically she didn't have anything left other than touch... And there we are sitting outside... six feet apart, and she can't even tell who it is over there. We can't touch her, nothing. (Fieber, 2020, para. 4, news article)

Welsh (2020c, news article) reported that "during the window-visit stage, one man thought his wife had abandoned him and grew deeply depressed" (para. 14). Similarly, a disabled young adult in a care home could not understand when "she reach[ed] out for a hug and no one lean [ed] in" (Roumeliotis & Mancini, 2020, para. 10, news article). For those who were hard of hearing and those with cognitive limitations, these restrictions added a layer of difficulty to existing communication challenges (Welsh, 2020c).

The separation of families imposed by COVID-19 restrictions in LTC also resulted in "another layer of suffering being brought on by the pandemic for families with loved ones isolated in long-term care" (Brunoro, 2021a, para. 3, news article). As Roumeliotis and Mancini (2020, para. 5, news article) reported, "from full lockdowns to the more recent restricted visits, many [family members] have spent the entire pandemic desperately trying to get closer to the ones they love." Family members have experienced distress, hopelessness, fear, anxiety, depression, insomnia, profound worry, and anguish; one family member in Vancouver told how "There's been times where I just started crying... It's just so overwhelming and the thing about it is not being able to help this person that you care about and their ability to help themselves is highly restricted" (Brunoro, 2021a, para. 6, news article). One daughter said, "she cries often, can't sleep and feels a constant sense of dread" (Roumeliotis & Mancini, 2020, para. 23, news article). Others described the restricted visitation as heart-wrenching, devastating, and agonizing uncertainty, "afraid every visit could be the last one for some time" (Roumeliotis & Mancini, 2020, para. 34, news article). Vivian Stamatopoulos, an associate teaching professor at Ontario Tech University, is quoted in an article by Roumeliotis and Mancini (2020, news article) saying, "Over my 10 years of studying caregiving, I've never seen anything like this kind of burden or trauma placed on caregivers... It's tantamount to a form of post-traumatic stress caused from forced helplessness" (para. 26). The CEO of a Nova Scotia care home summed up the feelings of separation by saying, "The residents are becoming very tired. They're wanting to see their families and the families are becoming very anxious as well and they want to see their loved ones" (Moore & Jerrett, 2020, para. 3, news article).

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Family members reported that "the prolonged social isolation from visitor restrictions to prevent the spread of COVID-19 is causing enormous harm to their mental and physical health" (Mahoney, 2020b, para. 5, news article). There are numerous references in this data set to the decline in physical health that many LTC residents experienced throughout the pandemic. As Welsh (2020c, news article) reported, "residents locked inside declined from isolation, losing weight, growing dehydrated and depressed" (para. 8) In other circumstances, "without the people they rely on, some residents have given up and lost the ability to walk or talk" (Welsh, 2020c, para. 10, news article).

Others observed that "nursing-home residents have died of dehydration and malnutrition amid allegations of neglect" (Mahoney, 2020b, para. 11, news article). One seniors' advocate explained that there were "cases of people who were essentially starving to death because they were not being either fed or they weren't getting the cues to eat" (D. Mitchell, 2020, para. 49, news article). Despite repeated expressions of concern to staff about her father's well-being, one daughter said it was obvious "that he was not being fed or being nourished or hydrated the way they had told me he had been for weeks" (Pedersen et al., 2020, para. 23, news article). Another family watched their father decline as a result of neglect, eventually dying of malnutrition—testing negative for COVID-19 five times (Glover, 2020, news article). One family member (January 2021) tweeted this: "My grandparent went 3 months w/o [without] a shower... LTC is in CRISIS. Ppl [people] are dying not just from COVID but from abandonment & [and] neglect. IT IS SENICIDE." One family—a daughter and granddaughters of a LTC resident—visited through a window, explaining:

My mom was so dehydrated, she had the call button in her hand and she was trying to drink from the call bell... I knew she was dying and I knew they wouldn't let me in till the last hours.... The only thing we could do was bang on that window—I was afraid my girls were going to break it—just trying to get help for Mom. (Pedersen et al., 2020, para. 68–69, news article)

A physician remarked that this was the first time in their career they had seen "inanition" listed as the cause of death on a coroner's report (Glover, 2020, para. 21, news article).

Residents' mental health has also been enormously affected (Welsh, 2020a, news article). Depression, loneliness, and confusion are reported throughout the data. Initial visiting restrictions eventually caused more harm than good (Bains, 2020, news article). Residents were often sad and lonely and family members were afraid they might die alone (Bains, 2020, news article). One staff member observed:

They're [residents are] more depressed. They might be less compliant to get up in the morning. They might not be smiling as much or start wandering a bit more, they might show a little bit more aggression. We're dealing with a lot of crying. (A. Mitchell, 2020, para. 17, news article)

An increased use of antidepressants and antipsychotics was noted (Bains, 2020, news article). One daughter described seeing her mom several months after the pandemic shutdowns began: "Her eyes were vacant. No smile, she didn't recognize me" (Brunoro, 2020, para. 6, news article). Advocates argued that some residents were dying from loneliness (Welsh, 2020b, news article) and maintained that the depression and loneliness caused by isolation were worse than the virus (Fieber, 2020, news article). A health policy and geriatrics expert quoted by Fieber (2020, para. 17, news article) pointed out that "we're seeing increasing rates of depression, loneliness, social isolation, and that actually can be even more dangerous" than getting the virus.

Ultimately, because of the lack of touch, the lack of family contact, the lack of socialization and social activities, people have been dying from COVID-19 without actually getting it (Fieber, 2020, news article). In too many situations, residents' final days are spent lonely and isolated (Mahoney, 2020a). One staff member tweeted (October 2020): "I work in LTC and retirement & [and] have hundreds of these patients. I can attest that many have died or are dying of social isolation." The geriatrics expert quoted by Fieber (2020, news article) noted that "most people living in these homes are within the last two and a half years of their lives. And I don't think this is how many bargained that they would be planning to spend the last two and a half years of their lives" (para. 11). He went on to explain how "some people are saying, 'Look, I know that I could get the virus and die, but I might rather have that, frankly, than not being able to be with my loved ones for the next six months" (Fieber, 2020, para. 17, news article). Corroborating this sentiment, one resident told her daughter: "I'm getting old and what time I have left, I don't really care about that [avoiding COVID-19]. I care more about spending time with family" (Mahoney, 2020b, para. 30, news article).

#### The role of family caregivers

The exclusion of family members from care homes led to questions about the role they play in the lives of their family members who live in LTC. Although it is clear from the data what role they play in social support, advocates have argued that family members are essential caregivers who fulfill a vital and essential role in the daily care and general well-being of LTC residents. One care home physician indicated that, "Throughout the whole pandemic, that has been the argument of family caregivers, that they should qualify as essential, it shouldn't just be for people at end of life" (Welsh, 2020c, para. 11, news article).

As mentioned above, the separation of family members and their loved ones in LTC had severe consequences for the physical and mental health of residents. This decline in health is directly related to the loss of the essential caregiving role played by family members. The daughter of a Toronto LTC resident explained that, shortly after her mother's care home closed to visitors, she "got news that she was barely eating or drinking and was on the verge of death" (Mahoney, 2020a, para. 10, news article). The mother, who had dementia, needed to be spoon fed and "always ate more when her daughter or private caregiver visited and had time to coax her to take another bite" (Mahoney, 2020a, para. 11, news article). This daughter worried about how "her mother would manage without extra help at mealtimes" (Mahoney, 2020a, para. 11, news article). The CEO of a LTC facility remarked that "We think of them [family] as part of our team. Before the pandemic, they helped with exercises, bathing and meals. When we lost that, we lost a lot of care hours" (Welsh, 2020c, para. 49, news article). The huge pressure on staff with the loss of family caregivers was acknowledged (Welsh, 2020c, news article). A resident expressed the need for more care, pointing out that "I need more help. I want somebody to help me to the toilet. I want somebody to help me eat. I want somebody who's going to sit and listen to me" (Bains, 2020, para. 9, news article).

According to a British Columbia woman, a caregiver for her mother, "We all want to be considered an essential caregiver and be able to go in... Whether it's helping them feed... helping them brush their teeth... just spending time with them" (Brunoro, 2020, para. 15, news article). In one example, a daughter explained that "Whenever I was visiting with my mom, I would help feed her. I would help her to go to the toilet. I would help her get dressed if she needed to, or would put her to bed" (Thompson, 2020, para. 10, news article).

Beyond assistance with daily living, one daughter explained that she was "not a visitor. I am her caregiver. I'm her power of attorney, I make all her decisions for her and I should be allowed to be with her" (Mahoney, 2020b, para. 4, news article). A staff member indicated that "we want to allow for these essential family care givers to be present, to have access, to be able to hold and touch and support, advocate for and participate in decision making" (Fieber, 2020, para. 37, news article). This highlights the broad range of practical support offered by families

from physical care to social support to advocacy. The role of family caregivers can be a matter of life and death and can protect against medical error (Fieber, 2020, news article). The practical importance of family caregivers was repeatedly acknowledged.

Frustrations with inconsistencies in visitation policies were expressed throughout this data. Welsh (2020c, news article) reported family complaints that staff can approach a resident with PPE but family members are not allowed, despite their willingness to be trained to use PPE. One daughter noted that a paid private caregiver was allowed to enter a facility to care for her mother but that the daughter was not permitted to enter, which was inconsistent in terms of risk management and failed to accomplish care goals because, for example, "my mother didn't want a hug from her (personal support worker). She didn't want a kiss from her (registered nurse)" (McQuigge, 2020, para. 29, news article). It was argued that evidence about infectious diseases indicated that it was possible to visit safely. One advocacy group recognized the importance of limiting general visits in LTC to stop the spread of the novel coronavirus but noted that essential family caregivers should be allowed into facilities and provided with the PPE, training, and support (Goldfinger, 2020, news article). A family member explained that "a meaningful visit is putting on PPE, being safe and going into your resident's room" (Brunoro, 2021b, news article). One family caregiver exclaimed:

I'm willing – just like all the other families – to do whatever it takes to keep our loved ones safe. Dress me up in full PPE, I'm willing to do it. I'm willing to do the COVID tests, I'm willing to do anything, but we need to have access to our loved ones. We need to be able to hold and touch and hug them. (Thompson, 2020, para. 24, news article)

In a tweet, one physician called for facilities to "Let any visitors in, 24/7, no appt [appointment], to see their loved ones [with] #COVID19 if they felt comfortable. I watched families sit in full PPE, holding their loved one's hands." This physician's argument went beyond daily care, not-ing that "It is possible to not die alone w/ [with] COVID" (December 2020, Twitter). Quoting a caregiving daughter, Thompson (2020, news article) illustrated:

This is not sustainable. We need to have a more workable solution because COVID is going to be with us for a while. I can see each visit, my mom is declining. I can't do anything. I can only see her once a week for half an hour. (para. 12)

Welsh (2020b, news article) reported that "policies must: recognize the difference between essential family caregivers and general visitors; balance the risks of COVID-19 with serious risks of social isolation; and give residents access to enough visits to maintain their health" (para. 17). The National Institute on Ageing called for balance between COVID risk and risks of social isolation (Bains, 2020, news article). Vivian Stamatopoulos, the previously-quoted professor who specializes in family caregiving, argued that restoring the role of family caregivers is "vital. This will save lives. There is no question about that. We absolutely need family because they are known to be a vital safeguard for residents... against abuse and neglect" (Mahoney, 2020b, para. 9–10, news article). One LTC leader argued that "they [the government] are failing to realize that we are in a very different place in July than homes were in March [2020] when they implemented these policies. So now is the time to safely reintegrate (caregivers)" (Welsh, 2020c, para. 34, news article).

#### Stress of healthcare workers

Healthcare workers have carried a significant burden through the pandemic, as reported in this media data. Reports indicate that they have been subject to extreme workloads, severe emotional distress, and unsupportive working environments.

The loss of family caregivers resulted in increased workloads for LTC staff. This compounded already severe staffing shortages in the LTC sector (Mahoney, 2020a, news article). Vacancies were also left by workers who had to isolate themselves because of COVID-19 exposure or who were too afraid to work because of the risk of infection (James, 2021, news article). Having to implement infection control precautions added to the workload. The staff had to treat every resident as if they had COVID-19, using gowns, gloves, masks, and face shields, and extra sanitization protocols (James, 2021, news article). James (2021, news article), writing from the staff member perspective, commented on the lack of training and the disorganization of the work environment. Some staff were required to work overtime without breaks (Binks-Collier, 2021, news article). In addition to an exploitative workload, there was a lack of PPE for staff (Perkel, 2020, news article).

Nurses and care workers also experienced severe emotional distress. They had to deal with their own fear of becoming ill, the fear of infecting their families (James, 2021, news article; A. Mitchell, 2020, news article), and separation from their families when they themselves got COVID-19 (Sachedina & Cousins, 2021, news article). As well, they had to manage the worry, confusion, and loneliness of the residents, and "pick up the slack" without family caregivers present (A. Mitchell, 2020, para. 7, news article). Residents were depressed, aggressive, tearful, and confused about why their families were not there, leaving staff to support and comfort them (A. Mitchell, 2020, news article). Binks-Collier (2021, news article) vividly reported the emotional depletion, burnout, distress, and sorrow experienced by the staff. James (2021, news article), a personal service worker, described how "rushing around constantly, unable to catch my breath, would often reduce me to tears. I would just have to run and hide somewhere to cry for a few minutes before I could get back to work" (para. 19). The bond with family was important to staff (Binks-Collier, 2021, news article). "[The staff] actually really miss the families. It isn't just the residents who miss the family but nursing staff as well" (Welsh, 2020c, para. 27, news article). The depersonalization of relationships with virtual visits, sometimes during residents' final days of life, led to distressing moments where staff members grieved for families but felt unable to help them (Binks-Collier, 2021, news article; James, 2021, news article). Nurses were involved in tough decisions—like which sibling would get to visit a dving parent (Grinspun, 2020a, blog post). James (2021, news article) described how "one resident would cry anytime they got to see their loved ones on a video call, and I [James] had to try so hard to hold back my own tears" (para. 10). In a moment of relief, one staff member tweeted (June 2020), "I'm so happy to see a small break in this damn covid pandemic and be able to watch the loved ones of the nursing home patients I provide medication for daily get to hold their parents/grandparent. Happy tears!" Although positive, this tweet reveals the connection staff feel with families and the emotional burden the staff carry for them. One physician reported that working in LTC during COVID-19 "was more difficult than caring for Ebola patients in the Democratic Republic of Congo" (Mahoney, 2020a, para. 6, news article). Some managed the emotional strain by "not letting [themselves] feel it completely" (A. Mitchell, 2020, para. 13, news article). Summing it up, one LTC worker described working during the pandemic as "a warzone... It was hell. It was complete, total hell" (Sachedina & Cousins, 2021, para. 3, news article).

Healthcare workers often labored within unsupportive environments. Perkel (2020, news article) described the work context as "authoritarian and hierarchical" (para. 11), with insufficient PPE provided to staff. "Interviews with nurses, personal support workers and others in hospitals and long-term care homes suggest chronic stress and burnout are common... fear of reprisals is stopping them from speaking out" (Perkel, 2020, para. 2, news article). Personal support workers (PSW) make up 85% of the LTC workforce; they are unregulated, poorly paid, mainly women, and most have second or third jobs (A. Mitchell, 2020, news article). The gendered dimension of this work was described by a PSW:

Healthcare has always been predominantly female[,] and we've been taken advantage of. We know how to do the job, we have a lot of tolerance, endurance and stamina. We're very loyal, very nurturing. And I believe that if staffing was more male, there would be more staffing, better pay grids, everything. (Brophy et al., 2021, p. 275)

Although some employers were supportive (A. Mitchell, 2020, news article), others demanded that workers return to work prematurely after being sick with COVID-19 themselves (James, 2021, news article). As James (2021, news article) commented, "the expectations of PSWs are unrealistic. We do such physically hard work and get paid so little. You can't realistically provide proper care to that many people" (para. 23).

Nurses and other staff in LTC worked to try to keep connections with families, reporting that patient- and family-centered care (PFCC) was even more important as a result of the visitor restrictions (Grinspun, 2020a, blog post). Staff found ways to facilitate connection between residents and loved ones by teaching people about social media, facilitating video calls, arranging window visits, and finding phones and tablets (Grinspun, 2020a, blog post). However, they also found these exposed inequities; when many people did not have access to phones or internet connections, they helped to arrange internet access and find free Wi-Fi or low-cost data plans (Grinspun, 2020a, blog post). The disconnect between values aligned with PFCC and the reality of the pandemic led to burnout and moral injury, as described in a blog documenting a panel interview with several nurses:

Nurses have spent their entire career focusing on patient- and family-centered care. They have wanted families at the bedside. They believe that no one should die alone. But they are now being told they can't let anyone at the bedside, even when someone is dying. The moral injury nurses feel when they tell a family member over the phone that they cannot visit can contribute to burnout. (Nitkin, 2020, Question Three, blog post)

#### Structural and policy issues

The suffering of residents, families, and staff has been (at least in part) the result of policy responses to the pandemic as well as structural issues within the health and social care systems. These policies and structural issues are embedded within a societal context that facilitated and perpetuated the lived distress.

As the pandemic continued, some governments reconsidered the role of family caregivers, ultimately arriving at different responses. Initial policy responses to the pandemic created a crisis (Mahoney, 2020a, news article) but restrictions began to ease as the pandemic evolved. In British Columbia, the government promised to hire more care aides to "process" visitors without taking away care hours (Brunoro, 2020, news article). As well, the British Columbia Ministry of Health reportedly clarified guidelines for essential visits, although the provincial health officer noted that it was challenging to operationalize a designated visitor policy (Brunoro, 2021a, news article). In Ontario, a private member's bill was initiated that would guarantee that those in care receive continuous and safe access to essential caregivers (Brunoro, 2021a, news article). The Nova Scotia health minister announced that restrictions previously in place were being eased to allow designated caregivers in, defined as those who "must provide the resident with support such as personal care, mobility, or help with eating, and have had an established caregiving relationship with the resident before the COVID-19 pandemic began" (Moore & Jerrett, 2020, para. 7, news article). Despite these policy attempts to improve circumstances, "some families believe it's too little, too late, and that they need help

right away" (Brunoro, 2020, para. 18, news article). Some LTC facilities went as far as hiring family members to help with feeding, socializing, companionship, housekeepers, and in food services (CBC News, 2020b, news article; MacKinnon, 2021, news article) to help with care of their loved ones and others and to help to relieve the staffing shortage.

The pandemic revealed the shortcomings of the LTC sector in Canada. Reportedly, 68%–82% of deaths attributed to COVID-19 in Canada have been in LTC (Mahoney, 2020a, news article; How to fix Canada's broken long-term care system, 2021, news article). Reasons given by the editorial board of one national newspaper (How to fix Canada's broken long-term care system, 2021, news article) for the high proportion of deaths among LTC residents were short staffing, poorly paid workers, inadequate resources, substandard facilities, underfunding, and a shortage of beds. According to the Ontario Community Support Association, as quoted by Ireland and Kalata (2021, news article), the home care sector could have helped lessen the load on struggling LTC facilities if it had been funded appropriately. With COVID-19 "exposing lethal weaknesses in the system" (Ireland & Kalata, 2021, para. 9, news article), "the benefit of increased home-care investment in Canada is getting long-overdue attention" (Ireland & Kalata, 2021, para. 9, news article). Indeed, people now seem to be questioning whether LTC is still a suitable option for a family member as they plan for the future (Goldfinger, 2020, news article).

Turf wars and discontinuities in care also created issues for the well-being of LTC residents during the pandemic. In some cases, family members were erroneously or deceitfully advised that there was a "no-transfer policy" in place, preventing sick LTC residents from being transferred to a hospital for lifesaving care (Payne & Duffy, 2020, news article; Pedersen et al., 2020, news article). In a news article by Levy (2021, news article), it was claimed that "turf wars and bureaucratic red tape kept two dozen Ontario infection control experts out of long-term care homes in the early stages of COVID-19 at a time when they were most needed" (para. 1). Reportedly, these infection control practitioners were told to "keep a low profile" when COVID-19 hit in March 2020, as a cost-saving measure that favored a different branch dealing with communicable diseases (Levy, 2021, para. 2, news article). These policy and practice decisions created a "lost opportunity" (Levy, 2021 para. 9, news article) that likely resulted in deaths (Pedersen et al., 2020, news article).

It was noted in this data that ageism provided a foundation for discriminatory practices, such as the no-transfer policy (Payne & Duffy, 2020, news article), and made it possible for "people [to] dismiss the elevated death rate among older people as 'fine,'" based on an internalized "notion that the elderly are frail, burdensome, and ultimately expendable" (Landau, 2021, para. 3–7, news article). Landau (2021, news article) reported that the "*Journal of American Geriatrics Society* has urged healthcare organizations to keep seniors' needs top of mind when it comes to clinical breakthroughs, policy and funding" (para. 17). Knowledge about the nature of and appropriate response to COVID-19 is constantly growing and evolving. Long-term care policies must keep up with new evidence. Many news articles in this data set reported the rise of advocacy groups and investigative commissions, and the growing involvement of academics in response to the harmful policies that have affected LTC residents, their families, and staff throughout the pandemic (Bains, 2020; Bench, 2021; Brunoro, 2021a, 2021b; Casey, 2020; Mahoney, 2020a; McQuigge, 2020; Roumeliotis & Mancini, 2020; Welsh, 2020b).

The urgency of the situation was made clear. According to Doris Grinspun of the Registered Nurses Association of Ontario, "Most long-term-care residents are very old and fragile and cannot simply put off such important contact with loved ones. Every minute counts. They cannot wait one more year. They cannot wait" (Welsh, 2020b, para. 12, news article). A family member expressed the urgency and desperation of the moment as well saying, "We don't have time for the vaccine rollout.... At almost 96 [her mom], every day's a gift and I would like to experience those with her" (Brunoro, 2021a, news article).

The issues in LTC that led to outbreaks and deaths were known prior to the pandemic (Grinspun, 2020b, blog post). In a guest blog post, Sebera (2020, blog post) wrote about the

myriad of problems in LTC that have been long-standing, including nurses and personal support workers caring for too many residents; reliance on part-time employees, which reduces continuity of care; that many people died from understaffing prior to the pandemic; and that staff burnout and turnover is so high it leaves this complex area of practice without needed expertise. This expertise, she argued, means there is "no one to pass on knowledge, judgment and skill, no one with experience and skill to stand up to management to insist that things be done safely" (Sebera, 2020, para. 7, blog post). Addressing the premier of Ontario, she further wrote:

In your speech, you made it sound as though these are problems that no-one knew about, that the problems are because of COVID. The problems with LTC were evident long before COVID. Nurses have known for at least 20 years how bad it is to work in LTC. (para. 14, blog post)

## DISCUSSION

In this research, we examined media and social media reports to understand the experiences of LTC residents, their families, and staff in relation to the visitor restrictions implemented in the COVID-19 pandemic in the Canadian context. Our findings were organized into themes of isolation, separation, and the health consequences of restrictions; the role of family caregivers; the stress of healthcare workers; and structural and policy issues. Our analysis paints a bleak picture of the state of LTC in Canada; those familiar with the Canadian LTC system will not likely find this surprising. The experiences of residents, families, and staff conveyed in this data have been challenging, heartbreaking, and injurious.

Older adults who live in LTC facilities bore a large burden during the pandemic. As was evident in the reports, many of them may have chosen to weigh their quality of life, and interactions with loved ones, as more important than protection from a COVID-19 infection. For some, being cut off from family resulted in severe physical and cognitive decline, and even death, without a COVID infection. Pandemic-related public health policies that restrict freedoms "must be proportionate to the harms" (Jeffrey, 2020, p. 145). Undoubtedly in LTC both the restrictions and the potential for harm in aggregate care settings were weighted more heavily than in younger populations, living independently. As Wammes et al. (2020) suggested, there is no consensus that the protective effect of visiting restrictions outweighed the adverse effect on resident well-being.

The policy decisions that restricted visitors to LTC had unintended consequences. Understandably, many policy decisions made at the beginning of the pandemic needed to be made hastily and without as much evidence to support them (e.g., the uncertainty about droplet versus aerosol spread and the need for face masks, a policy change made in Canada in November 2020; Miller, 2020). It seems, however, that principles of PFCC, such as shared decision-making, were disregarded in these early policy decisions. Family caregivers, for example, likely would have been able to explain the importance of their role and help to inform earlier decisions about essential caregivers having access.

There are likely long-term consequences for families who witnessed their loved one suffering from afar and were powerless to help them. There are predictions that the pandemic will lead to an increase in severe and prolonged complicated grief, and thus far, an increase in acute grief reactions have been noted (Eisma & Tamminga, 2020). Family member suffering could be further compounded by the circumstances around the death of a loved one in LTC. Families may rightly believe that if they had been allowed access to their loved one, the outcome would have been different (Bell & Wright, 2021).

It was not only pandemic related policies that led to the devastating outcomes in some LTC facilities, but a reflection of decades of policies that led to underfunding, understaffing, and an

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increasing reliance on family caregivers to provide basic care. Our findings here are supported by recent investigations by Estabrooks et al. (2020) who reported the LTC sector has increasingly relied on family and friends to provide unpaid care. These care providers are disproportionately women whose burden and need for respite is little acknowledged in COVID policy decisions (Estabrooks et al., 2020). Kemp (2021) stated, "policies and practices responding to COVID-19 in care settings indicate a failure to recognize the significant nature of family involvement and the consequences of their exclusion" (p. 145), further explaining that this failure "originates from taken-for-granted assumptions about gender, families, and care work" (p. 145). Brophy et al. (2021) concluded that patriarchal structures are hindering broad reform in LTC, which is largely comprised of a female, racialized workforce who are not listened to, respected, or provided with the tools to do their jobs, as pointed out in our findings. Béland and Marier (2020) described the potential opening of a policy window in Canada, which could allow for significant reforms to LTC. Although their focus on funding structures could address part of the underlying issue, our data strengthen Brophy et al. (2021), Estabrooks et al. (2020), and Kemp's (2021) positions. The staff experiences reported here are not unlike those from around the world. The OECD (n.d.) reports many LTC workers face difficult working conditions, low pay, and part-time, temporary, and insecure work. There are reports of nurses experiencing burnout and moral injury related to working during the pandemic from many countries around the world (Gray et al., 2021). Similarly, our data reveal traumatic, morally distressing situations faced by staff in LTC facilities.

These news reports that were part of our data tended to focus on negative aspects of the situation. There are some examples from recent research of more positive changes to the triad of residents, family members, and LTC staff. For example, Shajani and Snell (2021) found that nurses were engaging with a greater number of residents' family members because bringing in videoconferencing allowed them to communicate with family members who did not live nearby. Neiman et al. (2021) reported nurses took on numerous innovative roles to support families when visitor restrictions were imposed, such as around death and preparation of the body, and nurses found those encounters rewarding and educational. Yeh et al. (2020) found that if there was good quality care for residents in LTC, that family members were more satisfied, and there was less tension during the COVID-19 crisis and restrictions. Guidelines to welcome family back safely were developed in the United States (Bergman et al., 2020), and many jurisdictions in Canada have now revised access policies for essential caregivers and designated support persons (see Alberta Health Services, n.d.; Government of Alberta, 2021). Although our data did not present many of these positive stories, these findings point to possibilities of how to do better in LTC in the future-for residents, family members, and staff.

## LIMITATIONS

As is true of all research, this study is limited by the type of data collected. In the planning stages of this project, there were uncertainty and restrictions about the potential to recruit participants directly. The data we collected, and our analysis of them, represent what has been reported in publicly available media and how it has been presented. The news articles in our data set give voice mainly to family members of elderly nursing home residents. Residents' voices are represented much less often, as are staff members' perspectives. As well, some LTC residents are young and only one person below 65 was mentioned in this data. Future research could explore the perspectives of those less represented in our data. However, our findings are supported by and consistent with recent, emerging literature on experiences in LTC facilities in Canada and from around the world, which speaks to the validity of what is conveyed in these data.

# IMPLICATIONS AND CONCLUSIONS

Overall, the analysis revealed policy makers' disregard for the important role of family caregivers for keeping residents safe and healthy, resulting in pandemic policies that did not reflect values of PFCC. As others described, the significance of gender cannot be overlooked—women comprise most family and paid caregivers in LTC. Bell and Wright (2021) explained that advanced practice nursing with families means that nurses understand and can intervene at multiple levels of systems, whether this is individual, family unit, or larger care systems. In the analysis of these data, we propose that to improve care of residents and their families, the most appropriate target for intervention is the larger system. In particular, the patriarchal structures and policies that continue to devalue the caregiving work of women, whether they are unpaid family members or paid caregivers.

The policies and structures that allowed the conditions in LTC to deteriorate to the state they have were present long before the pandemic. Although, certainly, the infection of COVID-19 has led to deaths in older adults, the analysis of these data revealed that it was both COVID-related and pre-pandemic policies that contributed to deaths of people living in LTC facilities in Canada. We are hopeful that what we learned about family during COVID-19, because of their absence in LTC, will propel continued changes and improvements. In the very least, we can hope that the experiences of the COVID-19 policies in LTC remind us permanently that families are #morethanvisitors.

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