

CLINICAL RESEARCH

ISSN 2619-9017 | E-ISSN 2618-6535

and LONG-TERM CARE

JOURNAL of AGING

www.agingandlongtermcare.com • www.jaltc.net

"You Admit a Resident, You Admit a Family" The Impact of COVID-19 Restrictions on Family Time in Long-Term Care

TRACY CHRISTIANSON¹⁰, EVANS APPIAH-KUSI¹⁰, JORDAN BREMNER¹⁰, ANDREW FILEWICH²⁰, AMNA QAZI¹⁰, COLIN REID²⁰



2023, 6(3), 139-157 | DOI: 10.51819/jaltc.2023.1353633

1. Thompson Rivers University, 2. University of British Columbia

Received: September 6, 2023 | Accepted: December 30, 2023 | Publish Online: December 31, 2023 Correspondence: Tracy CHRISTIANSON

Thompson Rivers University, School of Nursing, 805 TRU Way, NPH 256, Kamloops, BC, V2C0C8, Canada Thompson Rivers University, School of Nursing, 805 TRU Way, NPH 256, Kamloops, BC, V2C0C8, Canada / tchristianson@tru.ca

ABSTRACT

Social connection is important for better health and wellbeing. However, the public health restrictions that were put in place due to COVID-19 disproportionately affected older adults, particularly those living in long-term care (LTC). Due to this unprecedented situation, the re-searchers aimed to understand the perceived impact of pandemic restrictions on families of residents in LTC facilities and shed light on how families perceive the strategies put in place to help families stay connected. Reporting data from semi-structured interviews with family members as part of a larger mixedmethods study, findings focused on themes of quality of life, quality of care, mental health concerns, communication, and the rules. The rules were an over-arching theme, and each of the interrelated themes describes the experiences of families feeling dismissed by the health system, stressed about being unable to support their loved ones, and helpless during the various lockdowns when staffing was additionally strained. These findings highlight how, being excluded from decision-making processes, family members and their loved ones were severely impacted by the COVID-19 restrictions and calls for policy changes to be inclusive of families as part of the care team in decision-making for LTC.

KEYWORDS: COVID-19; Restrictions; Policy; Long-Term Care; Family Caregivers; Social Connections; Canada; British Columbia.

KEY PRACTITIONER MESSAGE

- 1. Family caregivers are critical members of the healthcare team of residents in long-term care homes.
- 2. Public health COVID-19 guidelines restricted families from their loved ones who were living in long-term care from visiting in-care homes, leading to greater isolation among residents.
- 3. COVID-19 restrictions caused physical, emotional, and social harm to families and residents.
- 4. Governmental health policies related to public health restrictions specific to long-term care must be family-centered and inclusive of families in decision-making.

INTRODUCTION

While the Coronavirus (COVID-19) pandemic had a global impact and affected individuals, communities, and healthcare organizations, it struck long-term care (LTC) settings disproportionately hard. Older adults living in LTC facilities were at very high risk for mortality from COVID-19, especially due to workers and visitors who were unknowingly bringing in the virus and spreading it. For example, by May 2020, 81% of the Canadians who died from COVID-19 were older adults in LTC (Canadian Institute for Health Information [CIHI], 2020), with a mortality rate 13 times higher than older adults living in a community (Fisman et al., 2020); resulting in responsive public health measures. Public Health directives required LTC facilities to restrict visitors from visiting residents and pause many activities within these facilities. While these measures decreased the spread of the COVID- virus, they also had a negative impact on the residents' health and social well-being (Bethell et al., 2020; Chu et al., 2022). However, residents' family and friends in LTC settings as a "bedrock" of the system and essential care partners accounting for approximately 30% of the overall care in LTC, including feeding, washing, toileting, mobilization, and social, emotional and memory support (Tupper, 2020; Wolf & Jenkins, 2008) and resulted in residents' families being concerned about the COVID-19 restrictions implemented in LTC (Kemp, 2020).

Given that such restrictions were initiated when so little was known about COVID-19, the lack of family engagement/consultation about the restrictions demands consideration and understanding (Kemp, 2020).

In Canada, "Medicare" health care delivery is publicly funded through agreements with the ten provincial and three territorial governments to offer a wide range, but not inclusive, healthcare services and programs. However, while most of the health system is the responsibility of the provinces and territories, the federal government has a role in some health services, such as infectious diseases and health protection and disease surveillance and protection. Each province and territory is generally responsible for delivering health services in this intertwined and multilayered system. As such, services and directives are done at either the provincial/territorial and/ or regional levels, making the health care system delivery and communication challenging. With the rapid emergence of COVID-19 and the urgent need for those responsible to protect the most vulnerable populations by restricting family visitation in LTC, research on the impact this has had on families is emerging.

Objectives

A meaningful understanding of the psychosocial impact of COVID-19 restrictions on visitors in LTC facilities is emerging. It is also unclear what strategies

are effective in supporting families to remain connected. The researchers aimed to understand the perceived impact of pandemic restrictions on families of residents in LTC facilities, how families perceive the strategies put in place to help them stay connected, and determine if these were effective. The qualitative findings are presented in one-toone interviews as part of a more extensive mixedmethods study using a survey, interviews, and artsbased focus groups. Other data from the study will be reported in future publications.

METHOD

The researchers initiated this study during the second and third wave of the pandemic as visitor restrictions were evolving to include *"essential visitors."* The researchers followed the protocols approved (REB Certificate #H21-01256) by the harmonized research ethics board of Thompson Rivers University.

Participants

Participants included family members, guardians, or close friends with a loved one living in an LTC facility in British Columbia during the COVID-19 restrictions. The criteria for participation were adult family members over the age of 18 (relative, friend, and legal guardian) of residents who were or had been living in an LTC facility during COVID-19 within one of the five regional health authorities (Fraser Health, Interior Health, Island Health, Northern Health, and Vancouver Coastal Health). The participants resulted from a nested approach of a larger mixed-methods study where they were asked to participate in the second phase of the study and, for participating in both phases of the study, were entered into a draw for a gift certificate.

Data Collection

The gualitative data were collected through 60+ minute individual semi-structured interviews with participants until data saturation occurred. The interviews were conducted via telephone or virtually using primarily MS Teams to ensure COVID-19 protocols were maintained. Based on the literature (Kallio et al., 2016; McGrath et al., 2019; Ryan et al., 2009), one research member developed an interview guide, and the interdisciplinary team reviewed the guide for consensus. To ensure consistency in the interview data collection, the lead researcher reviewed the guide and interview process with the five other research team members. The guide was then pilot-tested with two non-participants to confirm that the questions were easy to understand and to determine the length of time to complete and make any adjustments to the overall interview process. Each of the five researchers was assigned participants to complete exploratory one-toone inter-views, using open-ended and probing questions to elicit information on how participants felt about the impact the restrictions had on their well-being and how they had contact with their loved ones in LTC. Interviews provided a unique and rich description of the *"lived experience"* of participants (Polit & Beck, 2004). The researchers audio-recorded all interviews and used the built-in transcription tool in MS Teams to ensure no detail was missed. The MS Teams transcriptions were verified with the recorded audio to ensure the accuracy of the content. However, to ensure confidentiality and anonymity, all identifying information was removed. Finally, each researcher was directed to maintain a separate file of their field notes that could be used as part of data analysis

Data Analysis

Interview data were analyzed using a thematic analysis approach and an inductive approach, where researchers explored data for patterns and themes. The transcripts were assigned to the research team who completed the interviews. Braun and Clarke (2006) guided the inductive thematic analysis as the individual researchers reviewed the transcripts to become familiar, developing codes or categories, looking for reoccurring themes, and describing those themes. Data was coded and themed independently. As part of the data analysis, the research team had several debriefing meetings to discuss the themes they had created. The final consensus of themes involved the team discussing, recording, and organizing the themes on a whiteboard. The research team's consensus ensured the confirmability of the data (Braun & Clarke, 2006). This process helped to establish rigor in this qualitative aspect of the study as each researcher was reflexive on the process and discussion of the results (Lincoln & Guba, 1986).

RESULTS

Descriptive Characteristics of the Participants

A total of 19 family caregivers volunteered for the one-to-one interviews, and of these, 16 were female. Most family participants were adult children (12), five were spouses, and one was a sibling, hence why the term *"loved one"* is used to describe the resident. Thirteen had a loved one living in care in Interior Health, and two in Vancouver Coastal, Island Health, and Fraser Health regions, representing four of the five provincial health authorities, respectively.

The interviews explored participants' experiences with the impact of COVID-19 restrictions in LTC and their ability to stay connected to their loved ones; however, they often described how COVID-19 impacted the residents. Five different themes were revealed through the thematic analysis of the data. The identified themes included several aspects, namely: (1) the assessment of quality of life, (2) the evaluation of quality of care, (3) the consideration of mental health problems, and (4) the examination of communication. These topics were unified by a fifth overarching theme, namely, (5) the adherence to rules and regulations.

Quality of Life

The theme of quality of life focused on the residents' rights to autonomy, self-determination, and the deterioration of the quality of life of family members. Participants described how their loved ones did not have input in their care decisions, and standardized care protocols implemented during the pandemic ignored the residents' right to make decisions about their care. For example, participant 6 powerfully described their view that their loved one's "basic human rights were taken away." Participant 1 elucidated that what was most terrifying was guickly realizing that when a loved one goes into care, "they stop being unique and become part of the care system." Such accounts of how their loved ones were unable to decide how they wanted to be cared for highlight how autonomy and self-determination were taken away, but it was the statement by Participant 03, who gut-wrenchingly described their experience, that depicted the impact on the quality of life of their loved one:

> "I think that mom died when she did because of the last two years. And just not having the quality of life that she could have if she weren't shut off from everybody."

The COVID-19 restrictions also negatively impacted the quality of life of family members of the residents.

Family members recounted how they missed celebrating precious moments like birthdays, anniversaries, and holidays with their loved ones, noting, "...as a family, we feel that the last nine months of his life were stolen from us" (Participant 7). Participants experienced a decline in their overall well-being as they were busy fighting for their ability to be with their loved ones. Participant 6, who had both parents in care, which added an extra level of concern, described, "Self-care was non-existent as I spent so many hours and days researching COVID-19 and was focused on seeing [reuniting with] my parents." Similarly, Participant 03 expressed "Sometimes I get myself to a point where I don't realize I need help, and then I find myself going sideways" resulting in an overall decline in their own health status. Such comments provide the significance COVID-19 restrictions played on the quality of life for families.

Quality of Care

Quality of care as a theme encompassed patientcentered care, family-centered care, advocacy, and staffing levels in the care facilities. At the height of COVID-19 restrictions, most participants lamented that governments and health organizations woefully disregarded the unique care needs of their loved ones. Participant 6 shared that *"The primary focus should be the needs of the residents, and it was not considered by the government."* Nevertheless, a few participants recounted that their loved ones received quality patient-centered care as staff were doing *"the best they could."* However, Participant 9 shared an experience of a loved one who received quality care, stating:

> "Well, I would say in long-term care, she got the best care. She really did. They were really good. But you would expect that for \$9000."

. In addition to providing family-centered care, most participants concurred that they were sidelined from actively contributing to the care of their loved ones. Due to the COVID-19 restrictions, most participants reported not being consulted or involved in the care of their loved ones. The participants explained that the non-involvement in their loved ones' care was alarming since they sometimes knew their loved ones well enough to be well-timed advocates for better services like switching medications or weight monitoring. The following quote was a common experience shared by the participants about being excluded from supporting their loved ones:

> "We were definitely fearful of the care happening behind closed doors [without the family involvement]" (Participant 6)

Participant 7 recounted,

"I checked his hearing aid, and low and behold, his hearing aid was broken. The tube going into the earmold had come disconnected. They had the ear mold in his ear. And then the hearing aid and the tube just over his ear, and it was disconnected," and Participant 6 expressed,

> "Only when the family is present and dealing directly with the care aide [is] where we get issues resolved."

These accounts suggest that if they had the opportunity to be included, the quality of care would have been sustained. However, some families hesitated to advocate for their loved ones because they did not want the staff to brand them as an *"aggressive family"* or a *"troublemaker."* For example, Participant 1 shared a painful experience:

"There's always this underlying thing, you know, for us saying we want to advocate, but we better be careful because we don't want any blowback."

With the staffing level and mix, most participants reported the inadequate number and rotating staff to care for their loved ones. They further added that the staffing issue was evident with the high staff-toresident work ratio and the long wait times before they got to talk to staff about their loved ones whenever they phoned the care facility. Also, some participants described how the constant use of temporary staff was inconvenient, particularly for residents with cognitive impairment. Below are some examples of this inconvenience:

I don't think [they] had adequate staff.

They were very hard to get in touch with. Whomever the director was in there, she was off on holiday for most of the time that mom was there. They had new administrators that didn't know what was going on. (Participant 9)

Other participants described the effect of the strained staffing on their loved ones, noting the frequency of showers being diminished or absent, the lack of time due to high staff-to-resident ratios, and the constant staff turnover as examples of the impact of the restrictions on the quality of care.

Mental Health Challenges

Both residents and family members experienced some form of mental health challenges. Four codes were captured under the theme of mental health challenges. Most participants agreed that the grief experienced by their loved ones (residents) was the most prominent trigger for residents' mental health decline. Due to the residents' prolonged exposure to isolation by the COVID-19 restrictions, the participants reported that residents became irritable, depressed, unhappy, and confused. Participant 9 stated,

> "I think...isolation just made things much more difficult. She was quite unhappy being on her own. There was loneliness and depression."

Participant 7 expressed,

"Many of the residents felt that their families

had absolutely abandoned them, and they were imprisoned. It's just kind of, you know, we're stuck here. Nobody could come to see us, and we could not go out to see anybody either."

Another contributing factor to residents' mental health decline was the ineffective support system for the residents. The COVID-19 restrictions heavily impacted the support systems that were in place before the pandemic. Participant 1 shared that residents had no mental health support within their care facility because the resources for mental health were available outside the care facility. Participant 6 also shared that there was *"no physical contact, no outside stimulation, such as drives, coffee or lunch out, no walks, and no sunshine"* for the residents. In contrast, some participants reported that some care facilities hired more staff to support their residents.

> "the facility that we were at [...] had extra staff coming in to do one-on-one visits with people [residents], and my mom really responded to that."

The COVID-19 restrictions halted all social interactions among the residents. The sudden and prolonged detachment from families and friends indisputably impacted the cognitive well-being of the residents.

Participants reported that social events like games night, monthly birthday celebrations, and church services, among others, were all canceled, and residents were just kept in their rooms. While all participants recognized that their loved one's cognitive health would not improve in LTC, they did not expect the rapid decline they witnessed during the pandemic. Participant 9 noted, "I think that the long isolation certainly led to a much faster decline mentally than we should have expected," while Participant 12 expressed, "I think it's progressing the way it would have, but I think it's because of the lack of visitation at that time. It probably got worse, faster." Participant 19 described their mother's experience of being put on symptoms isolation even after testing negative for COVID-19, which required her to be isolated from the other residents,

> "...she just started sobbing like she just burst into tears. She was sobbing, and she was like, Please take me out of here. Please take me out of here. I can't be here. I'm gonna die if I stay here."

Such examples highlight how family members viewed the effect on their loved one's mental health and well-being.

Guilt was another effect that impacted the mental well-being of families. Many participants reported feeling they betrayed their loved ones by abandoning them in the care facilities. Some participants also said their loved ones' accused them of intentionally leaving them in the care facility, accentuating their guilt. Participants described feeling guilty about not being able to provide care to their loved ones and missing out. *"It's disheartening and frustrating for me, and I was just kind of like if only I could be there"* (Participant 7), and Participant (19) shared,

I've seen my mom weigh less than I did before it's so just kind of that, you know, the grief around losing those two years with a mom who's almost turning 90. It feels like I've lost two years of really good quality time I could have had with her, and you know, that makes me feel really sad and, and quilty.

Communication

Most participants lamented how communication was ineffective within the care facilities across all levels during the COVID-19 pandemic. The communications were between the care facilities and the family, residents and the family, residents and the staff, and the staff and the family. Also included were participants' concerns about the communication of government, health authorities, and care facilities. With communication between the care facility and the family, most participants agreed that management could have done a better job of quickly instituting policies that would keep their residents safe and, at the same time, and stay in touch with their families about changes. For instance, numerous participants questioned why the management of care facilities did not announce earlier that COVID-19 vaccination would be required or the implementation of rapid testing and screening for visitations.

Communication between the residents and the family was strained during the restrictions. Some participants, particularly families that were not comfortable with technology, reported that communication was non-existent for them during the early stages of COVID-19 restrictions because they did not use newer forms of technology and felt cut off from their loved ones. Participants were asked about the communication strategies implemented to help maintain the connection between families and residents. When asked about what strategies were used and how useful these were to communicate and stay connected, participants noted a mix of strategies used by the care facility. Some strategies, for example, included telephone, in-person visitations (window or socially distanced), and video calling (Zoom or Facetime). However, the most preferred method was in-person visitations. For instance, participant 2 noted they could take their loved one outside to the facility courtyard with face masks during the summer. Some participants also reported that, although they were happy to be in the same room (socially distanced) with their lovied ones, they were appalled by the fact that staff had to be in the room to supervise. Participant 14 shared,

"There would be a woman sitting in the corner listening to our conversation, and I'd say, there's a window in the door [...]. Why can't you stand outside and check to make sure I wasn't hugging him."

The implemented window visits were generally ineffectual, where families were outside the LTC home looking in while offered some comfort as they could see their loved ones. Participant 19's analogy was poignant:

> "It's almost like when you're in the candy store and you really want the candy and you're not allowed to touch it. You can only look at it. It's kind of how it felt like I wanted nothing more than to give my mom a giant hug."

Participants noted that they were heartbroken because they could only watch their loved ones deteriorate. They were also frustrated with these strategies because of the procedures to set up such visits, as Participant 08 described,

> "...you've got to phone ahead, and you've got to book a time, and then you're only allowed to do that maybe twice a week....because [they say] we're busy and we have lots of window people. We have lots of people to deal with them, and we can't do it all the time."

Technologically-savvy families reported that

technology helped them stay connected with their loved ones during the COVID-19 restrictions. However, some participants noted that the strategies generally fell short of effectiveness due to their loved one's cognitive, hearing, or visual impairments. For example, *"Facetime - it did not work for us. My mom is classed as legally blind due to her macular degeneration. My dad did not understand why we weren't there in person"* (Participant 6). Other participants found the use of telephone and online communication challenging because their parents had cognitive impairment and could not comprehend why they were not physically there. Overall, most participants tried audio calling but described such communication as *"inadequate."*

Communication between the residents and staff was plagued with many barriers. Notable among the obstacles was the mandatory use of face masks. Most participants described how their loved ones had some hearing impairment and relied on lip reading. With the mask on, lip reading and reading facial cues were no longer possible. For example, Participant (7) described:

> "My husband relied a lot more on reading people's lips and facial expressions and wearing a mask; I found these residents never saw smiling faces anymore. They couldn't read facial expressions, and their [staff] voices were very muffled due to the

mask."

However, some participants talked about how some individual staff helped to keep them updated about their loved ones. Participants shared how the care aides were not supposed to tell them anything about their loved ones, but they would because they cared about the residents.

The manner in which the personnel interacted with the families was indistinguishable from the approach used by the management in their communication efforts. Most participants reported feeling "rushed" or "ignored" when calling to check on their loved ones. As participants recounted their experiences, they described how it felt like a fight to get information or access to their loved ones. However, some staff were responsive and informative with families, as Participant (2) noted, "As best as they could, they told us about her week and progress." These anecdotes demonstrate the general challenges of communicating with staff.

When participants had concerns and wanted someone in a position of authority to know, they felt their voices were not being heard. Participant 08 stated, "I had no confidence whatsoever that my concerns were being relayed by the management to anybody. They were just nodding their heads." Participants used the terms "vilified," "hindrance," and "enemy" to describe their feelings about their experiences in attempting to communicate with staff and management. As

Participant 01 stated, "We are not the enemy...we deserve to be heard." Many participants shared that they would try contacting the care home, and sometimes staff would answer the phone, and sometimes they would not, with several messages unreturned. Once the restrictions were starting to ease and "essential visitors" were being allowed in, this too created much grief as communication from the government, health authorities, and facilities was confusing and sometimes lacking. It appeared that each facility interpreted the policies somewhat differently, even within the same health authorities.

The Rules

There was an overarching and unifying theme about the rules. The rules refer to the restrictions and policies that were implemented during COVID-19. Although a few participants described the restrictions as "justified," most of the participants described the restrictions and policies as "inconsistent," "ineffective," and "inhumane." What became evident from participants was the variation in such rules between facilities and health authorities, and these variations also applied to public and private facilities. The inconsistencies resulted from the rules from the government and province to health authorities and the care facilities being open to interpretation. This made it unfair for some residents and families in facilities with overly protective management. For example, participant 12 shared, "They were trying to do the best they could. They were a bit slow in implementing the changes as Bonnie Henry [BC Provincial Health minister] announced them." Again, a participant lamented why they would not allow her family of four to visit her mother, yet 10,000 people could converge on Rogers Arena for a sporting game. Others noted that many of the rules did not make sense. For example, some facilities within the same health authorities did not use the same visitation policies. Participant 08 noted how staff and volunteers could come and go all over the facility into different areas, but a family member could not come into the facility to visit their parent in a private room. Whereas in the same health authority but in a different services area, Participant 13 could go in every day, noting they visited most days. Participant 19 described their feelings being up and down about the visitation restrictions, stating that,

> "as time has progressed, I felt a lot more anger over the inconsistencies in the implementation of the restrictions across facilities and health regions. Like, it feels like there's no kind of person that oversees all of this; it's just kind of someone, and each health authority assigned to it and all the rules are different and even within a health authority. The facilities all seem to be doing different things, and that has really been annoying for me."

As *"essential visitors"* policies were created, this also caused much frustration and confusion. Their spouse was immobile and incapable of feeding themselves, but their friend was not getting essential visitor status because their spouse was mobile and could eat independently. They highlighted that an essential visitor was solely there to help the care staff meet only the basic needs of residents.

With the ineffectiveness of the rules, some participants noted that even after sacrificing all dimensions of health to keep residents safe, some still died, and most did not feel safe but felt rejected and alone. Participant 07 described that when her spouse's health deteriorated and even in palliative care, the family could only visit one person at a time and would pass one another in the lobby, debriefing each other as they switched visiting roles while they watched their loved one die. Participant 08 stated "they would have to call the police to keep me from my dying wife." The purpose of imposing the COVID-19 restrictions was to keep residents safe.

Participants reported that their loved ones were not safe since some died, some experienced a faster decline in cognition, and some became incapacitated due to prolonged inactivity, and most of the participants reported that their loved ones had experienced a fall during the lock-down. Participant 11 encapsulated the feelings of all participants, stating, "We're not saving them [by] putting them in a plastic bubble, keeping them away from everything and everyone."

All participants agreed that the COVID-19 restrictions imposed were inhumane to the residents. All participants expressed that isolating them from their loved ones should not happen. Some participants reported that it was cruel to treat the residents like prisoners, lock everyone in, and lock out families, which was "like they were in prison... in some penitentiary." Key excerpts from some of the participants highlight the pain the restrictions caused families with Participant 01 stating, "If we had infants and young children in [...] care homes and the numbers we have in Canada of seniors in care and treated them like we do to our seniors, there would be people protesting in the streets" and Participant 11 asserting that "They're abused, as far as I'm concerned, by having the people they love kept away." Participant 03 summarized the feelings of all participants, stating,

> "...no matter what, when someone gets to the point where they're frail and needing LTC, you're not just moving in one person, you're moving that whole family. ...so all policies must be...family-centered. It cannot continue."

Finally, the idea of *"othering"* surfaced in the results. Participants felt excluded from decision-making on

the rules, policies, and restrictions and what was best for them and their loved ones. Participant 18 described this as "othering." All participants raised questions about the various and evolving decisions made by government and health officials. For example, Participant 08 questioned why policies did not consider residents' mental health sufficient for them to be designated as essential visitors, given that essential visitor status had to do mostly with those who needed assistance with eating. Several participants described how decisions were made without regard for them or their loved ones, stating, "we're not the enemy," "we are part of the circle of care," they were an "important part of the care team," and that they "need to be heard," suggesting that governments knew what was best for families of and residents living in LTC not the families. Most participants also voiced the need for family councils and/or adjudicators when families have questions or issues, suggesting such a strategy would offer families a voice in decision-making regarding care delivery in LTC. As Participant 18 stated,

> "we can't fix the past...[they] better do better next time."

DISCUSSION

The findings from this study contribute to the growing evidence of the impact COVID-19 restriction policies have had on families with loved ones in LTC while offering insight into improvements for the remainder of the current pandemic and preparing for future pandemics. The results uncovered five themes that help to explain family members' experiences. These themes highlight that while each participant had somewhat unique experiences, the COVID-19 policy restrictions impacted all participants consistently. Similar evidence has emerged and suggests policies about LTC restrictions must be revisited and be made inclusive of the needs of families and residents of LTC, emphasizing inclusive perspectives of families in the delivery of care and decision-making.

Since the beginning of the COVID-19 restrictions in early 2020, the emerging literature has drawn attention to the negative consequences the restrictions have had on families and residents in LTC. Researchers and advocates have been calling on governments, health authorities, and organizations to make the necessary changes to correct the wellmeaning but short-sighted public health measures that continue to have such adverse effects (Chu et al., 2022; Daley et al., 2022; Hugelius et al., 2021; Mitchell et al., 2021; Nash et al., 2021). The experiences shared in this study corroborate those of other studies that continue to highlight the effects on the physical, mental, and social well-being of families and the longterm consequences of such policies (Chu et al., 2022; Daley, 2022; Mitchell et al., 2021; Nash et al., 2021). The themes discovered in this study demonstrate the inter-relatedness of the impact of the COVID-19 restrictions and how they manifested in family experiences. Being kept from loved ones caused great stress, grief, and anxiety that was compounded by the lack of communication with their loved ones and the care staff. Good communication has been linked with a greater sense of ease and confidence in the care being provided and reassures families that their loved one is being well-cared for and is recommended for keeping families informed about LTC residents' care (Daley et al., 2022; Nash et al., 2021). While efforts to keep families informed and connected had some benefit in maintaining the emotional and social needs of families and their loved ones, in some cases, these efforts were ineffectual, resulting in increased stress and anxiety.

The ongoing lack of adequate staffing in LTC (Chamberlain et al., 2016; Rowmanow, 2002) exacerbated by the pandemic and support needed for implementing necessary communication strategies demonstrates the need for improved human resource planning going forward as others have similarly discovered (Dupuis-Blanchard, 2022; Gallant et al., 2022). Even so, the significance of individualized communication is critical for families.

Furthermore, the descriptions of the quality of life and mental health impacts on families and loved ones living in LTC cannot be emphasized enough. Social isolation due to the COVID-19 restrictions was a burden on family members. Families felt guilty for being unable to be with their loved ones, keep them company, and offer social support. The perception that loved ones had been abandoned and living a non-existent life weighed heavily on families. Family members felt themselves or their loved ones perceived them as responsible for the condition or environment in which their loved ones found themselves. Similar findings have recently been presented that further describe such experiences as traumatic due to the effects of COVID-19 related stressors of uncertainty, social isolation, lack of autonomy, loss, and others (Chu et al., 2022; Nash et al., 2021).

In a scoping review on the mental health impacts of COVID-19 on the social connection of residents in LTC, researchers discovered 61 articles that found an association between social connection and mental health outcomes (Bethell et al., 2020). Unsurprisingly, families in this study also experienced decreased quality of life and mental well-being. Results are aligned with those of Nash and colleagues (2021), who found that family members had an increase in mental health diagnoses, with 38% reporting depression and anxiety. The worry and concern for their loved one's health and social well-being for whom they were restricted from visiting, in conjunction with the evidence in the literature,

indeed leads to the deduction that the public health restrictions negatively impacted families and require significant improvements to ensure further trauma does not occur.

Moreover, this study adds that families are important members of the care team and should be treated as such, going beyond just visitors. Family members' contribution to the care of their loved ones was significantly restricted during the pandemic. The restrictions resulted in even greater staffing shortages than were present prior to the pandemic (Chamberlain et al., 2016; Ontario Ministry of Health & Long-term Care, 2008; Rowmanow, 2002). Families wanted to be a part of the care team during the pandemic because they felt they could contribute to the care needs of their loved ones and help decrease the burden on staff. This is not surprising, given that family caregivers provide nearly 30% of all care for residents (Tupper et al., 2020; Wolf & Jenkins, 2008) and have implications for future practice in LTC.

The overarching and unifying theme about the rules resulted in family members being excluded from decision-making processes; there were negative consequences due to COVID-19 restrictions. Although instituting the COVID-19 restriction rules was well-meaning, results from this study and others indicate that both families and loved ones were negatively impacted (Chu et al., 2022; Daley et al., 2022; Dupuis-Blanchard et al., 2021; Mitchell et al., 2022). Families reiterated that due to the evolving, confusing, and often inconsistent COVID-19 rules between LTC facilities and health authorities, they had to be vigilant in staying informed about their loved one's care and the current rules that were in place.

Kemp (2020) argued that classifying families as "visitors" takes a narrow view of what health truly means and negates families' vital role and contribution to LTC. Further, the "essential visitor" rule had serious flaws and lacked recognition of the value of family members being more than visitors. Such policies caused more harm than good as they attempted to protect residents from the potential harm of a virus but at the cost of quality of life and mental and social well-being (Chu et al., 2022; Dupuis-Blanchard et al., 2021; Gallant et al., 2022) while removing resident and family autonomy via "othering," and highlight the need to ensure future policies consider families' perspectives.

Limitations

Although data was collected during COVID-19 and participants' experiences were "fresh in their minds" with recent recall, they self-selected into the study and may have a vested interest in the topic, leading to potential bias. While families represented four of the five health authorities, the number was small, and views may not be representative of a larger population; however, collecting and reporting on

the lived experience of people related to a specific phenomenon bring their unique perspectives, and these can help shape future policy and/or practices. An important facet of qualitative studies is the degree of rigor (credibility, dependability, confirmability, and transferability) demonstrated, and some aspects of rigor may have been missed. However, the researchers attempted to establish credibility and confirmability by establishing the researchers' authority, interview process, and techniques (including triangulation) and ensuring the collection of field notes and reflexive research team debrief meetings (Lincoln & Guba, 1986). For dependability, the research team provided a detailed description of the study protocol, an audit trail of data, and an intercoding process (Lincoln & Guba, 1986).

Finally, as part of the researchers' larger study, there was an attempt to apply transferability. Though the response rate was small and cannot confirm data saturation in other contexts or settings, the findings are similar to those reported in the literature.

CONCLUSION

This study provides added evidence of the experiences of families with COVID-19 restrictions of access to their loved ones living in LTC. The findings illustrate the harmful impacts on families and residents and are relevant for practice and policy related to ongoing and future restrictions in LTC. Both provincial and federal governments now have lessons learned and research evidence that can rectify their actions of restricting families from their loved ones. This study adds to advocates' calls and the evidence demonstrating that families' and residents' physical and mental well-being is of utmost importance in policy development. Correcting and improving policies will need to include families and residents in the conversation on what needs to be done, focusing on " family-centered " policies.

While health organizations developed action plans and policies as the pandemic unfolded, there was disregard toward families and residents in these settings. Families are essential members of the caregiving team, yet they and their needs were dismissed and treated without regard, but they could have been instrumental in supporting residents and overworked staff and the strained healthcare system. It is vital to improve care delivery in LTC with an emphasis on "family-centeredness" and to build pandemic/visitor restriction plans and policies to prepare for ongoing and future outbreaks and pandemics. Families and residents deserve much better.

Acknowledgment: The researchers would like to express their sincere gratitude to the family members who participated in each phase of this study. Their views and experiences have highlighted their distress with the healthcare system and the ongoing dedication and love they provided to each of their loved ones living in long-term care.

REFERENCES

- Bethell, J., Aelick, K., Babineau, J., Bretzlaff, M., Edwards, C., Gibson, J., Hewitt Bolborne, D., Iaboni, A., Lender, D., Schon, D., McGilton, K. (2020). Social connection in long-term care homes: A scoping review of published research on the mental health impacts and potential strategies during COVID-19. JAMDA, 22, 228e237 https://doi.org/10.1016/j.jamda.2020.11.025
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research* in Psychology, 3(2), 77-101. https://doi. org/10.1191/1478088706qp063oa
- Canadian Institute for Health Information [CIHI] (2020). Pandemic experience in the longterm care sector: How does it compare with other countries? Canadian Institute for Health Information. https://www.cihi.ca/sites/default/ files/document/covid-19-rapid-response-longterm-care-snapshot-en.pdf
- Chamberlain, S. A., M. Hoben, J. E. Squires, and C. A.
 Estabrooks. (2016). Individual and Organizational
 Predictors of Health Care Aide job satisfaction in
 long term care. BMC Health Services Research,
 16(1), 577. https://doi.org/10.1186/s12913016-1815-6

- Chu, C. H., Yee, A. V., & Stamatopoulos, V. (2022). "It's the worst thing I've ever been put through in my life": The trauma experienced by essential family caregivers of loved ones in long-term care during the COVID-19 pandemic in Canada. International Journal of Qualitative Studies on Health and Well-being, 17(1), 2075532. https:// doi.org/10.1080/17482631.2022.2075532
- Daley, S., Akarsu, N., Armsby E., Farina, N., Feeney,
 Y., Fine, B., Hughes, L., Pooley, J., Tabet, N.,
 Towson, G., Banerjee, S. (2022). What factors have influenced quality of life in people with dementia and their family carers during the COVID-19 pandemic: A qualitative study. *BMJ Open 12*(2), e053563. https://doi.org/10.1136/
 bmjopen-2021-053563
- Dupuis-Blanchard, S., Maillet, D., Theriault, D., LeBlanc, F., & Bigonnesse, C. (2021). "Be their advocate": Families' experience with a relative in ltc during the COVID-19 pandemic. *Canadian Journal on Aging, 40*(4), 628-638. https://doi. org/10.1017/S0714980821000398
- Fisman, D., Bogoch, I., Lapointe-Shaw, L., McCready, J., Tuite, A. (2020). Risk factors associated with mortality among residents with coronavirus disease 2019 (COVID-19) in long-term care facilities in Ontario, Canada. *JAMA Network Open, 3*(7), e2015957. https:// doi.org/10.1001/jamanetworkopen.2020.15957

- Gallant, N., Hardy, M-S., Beogo, I., Conklin, J., Connelly, D., Kaasalainen, S., Keefe, J., Roitaille, A., Yous, M-L., Fanaki, C., & Cameron, C. (2022).
 Improving family presence in long-term care during the COVID-19 pandemic. *Healthcare Quarterly, 25*, 40-46. https://doi.org/10.12927/ hcq.2022.26980
- Hugelius, K., Harada, N., & Marutani, M. (2021).
 Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. *International Journal of Nursing Studies*, *121*, 1-10. https://doi.org/10.1016/j.
 ijnurstu.2021.104000
- Kallio, H., Pietila, A.-M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72(12), 2954-2965. https://doi.org/10.1111/ jan.13031
- Kemp, C. (2021). #MoreThanAVisitor: Families as "essential" care partners during COVID-19. Gerontologist, 61(2), 145-151, https://doi. org/10.1093/geront/gnaa161
- Lincoln, Y., & Guba, E. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation, 30*, 73-84. https://doi.org/10.1002/ ev.1427

- McGrath, C., Palmgren, P., & Liljedahl, M. (2019). Twelve tips for conducting qualitative research interviews. *Medical Teacher, 41*(9), 1002-1006. https://doi.org/10.1080/014215 9X.2018.1497149
- Mitchell, L., Albers, E., Birkeland, R., Peterson, C., Stabler, H., Horn, B., Cha, J., Drake, A., & Gaugler, J. (2021). Caring for a relative with dementia in long-term care during COVID-19. *JAMDA, 23*, 428-433. https://doi.org/10.31219/ osf.io/2qbhw
- Nash, W., Harris, L., Heller, K., Mitchell, B. (2021). "We are saving their bodies and destroy-ing their souls.": Family caregivers' experiences of formal care setting visitation re-strictions during the COVID-19 pandemic. *Journal of Aging and Social Policy, 4-5*, 398-413. https://doi.org/1 0.1080/08959420.2021.1962164
- Ontario Ministry of Health and Long-Term Care (2008). People Caring for People: A Report of the Independent Review of Staffing and Care Standards for Long-Term Care Homes in Ontario. Toronto: Queen's Printer for Ontario. https:// www.health.gov.on.ca/en/common/ministry/ publications/reports/staff_care_standards/ staff_care_standards.aspx
- Polit, D. F., & Beck, C. T. (2004). *Nursing Research:* Principles and Methods. Lippincott Williams & Wilkins.

- Romanow, R. 2002. Building on Values: The Future of Health Care in Canada - Final Report. Ottawa: National Library of Canada. https:// publications.gc.ca/collections/Collection/ CP32-85-2002E.pdf
- Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: The one-to-one interview. *International Journal of Therapy & Rehabilitation*, *16*(6), 309-314. https:// doi.org/10.12968/ijtr.2009.16.6.42433
- Tupper, S., Ward, H., & Parmar, J. (2020). Family presence in long-term care during the COVID-19 pandemic: Call to action for policy, practice, and research. *Canadian Geriatric Journal*, 1(23), 335-339. https://doi. org/10.5770/cgj.23.476
- Wolf, D. A., & Jenkins, C. (2008). Family care and assistedliving.InS.M.Golant&J.Hyde(Eds.),*The AssistedLivingResidence: A Vision for the Future* (pp. 198-222). Johns Hopkins University Press.