

COVID-19 and Long-Term Care: the Essential Role of Family Caregivers



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ABSTRACT

Background

Those most at risk from severe COVID-19 infection are older adults; therefore, long-term care (LTC) facilities closed their doors to visitors and family caregivers (FCGs) during the initial wave of the COVID-19 pandemic. The most common chronic health condition among LTC residents is dementia, and persons living with dementia (PLWD) rely on FCGs to maintain their care provision. This study aims to evaluate the impact of visitor restrictions and resulting loss of FCGs providing in-person care to PLWD in LTC during the first wave of the COVID-19 pandemic.

Method

An online survey and follow-up focus groups were conducted June to September 2020 (n=70). Mixed quantitative (descriptive statistics) and qualitative (thematic analysis) methods were used to evaluate study data.

Results

FCGs were unable to provide in-person care and while alternative communication methods were offered, they were not always effective. FCGs experienced negative outcomes including social isolation (66%), strain (63%), and reduced quality of life (57%). PLWD showed an increase in responsive behaviours (51%) and dementia progression. Consequently, 85% of FCGs indicated they are willing to undergo specialized training to maintain access to their PLWD.

Conclusion

FCGs need continuous access to PLWD they care for in LTC to continue providing essential care.

Key words: COVID-19, family caregiver, long-term care, access, dementia

INTRODUCTION

To mitigate the serious and often fatal effects of COVID-19 on older adults (age 65 yrs and older), Provincial Health Ministries across Canada enacted public health measures

resulting in reduced/eliminated visiting access to assisted/supportive living and long-term care (LTC) facilities. Although restrictive visiting guidelines have been adjusted to allow for more family caregivers (FCGs) to enter facilities, with the fluctuating rates of COVID-19 infection this may once again threaten access.⁽¹⁾ Adults over 60 years of age are at greater risk of developing severe COVID-19 infection symptoms that may require hospitalization (71% of hospitalizations), admittance to an intensive care unit (ICU) (63% of ICU admittance), and even death (97% of deaths).⁽²⁾ In Canada, 75% of COVID-19 associated deaths have occurred in LTC facilities.⁽³⁾ In June 2020, the Canadian Institute of Health Information reported that Canada had the highest proportion of COVID-19–related deaths occurring in LTC of all the countries in the Organization for Economic Co-operation and Development.⁽⁴⁾ Deficiencies in the Canadian LTC sector have been highlighted as contributors to the current situation including: 1) unstable financing, 2) lack of oversight and data collection, 3) outdated facility design, 4) lack of training for health-care providers, 5) a low ratio of health-care providers to residents, and 6) low wages and job insecurity for care aides requiring them to work at multiple sites, thereby increasing the risk of COVID-19 transmission.⁽⁴⁻⁶⁾

Residents of LTC facilities have increasingly complex health profiles with multiple comorbidities and chronic health conditions.⁽⁷⁾ The most common chronic health condition is dementia, which impacts 69% of Canadian LTC residents.⁽⁸⁾ Dementia is characterized by progressive neurocognitive impairment that impedes the ability to perform everyday life tasks, which causes persons living with dementia (PLWD) to become increasingly reliant on caregivers for support.⁽⁹⁾ PLWD in LTC are supported by formal care staff, but many also rely on the support of family or friend caregivers (FCGs). FCGs provide essential care for PLWD in LTC through daily care tasks, emotional support, and advocacy.⁽¹⁰⁾ During the COVID-19 visitor restrictions, the absence of FCGs has negatively impacted the provision of care for LTC residents resulting in decreased functional ability and cognitive decline.^(1,11-13) In addition, there are known negative health impacts of social isolation on PLWD and their FCGs.^(1,14-20)

The restricted access policy of LTC facilities during the initial COVID-19 outbreak in Canada changed care provision and roles of FCGs in LTC. These policies were unique to the COVID-19 pandemic.⁽¹⁵⁾ During the H1N1 pandemic in 2009–2010, the Public Health Agency of Canada published guidelines around infection control with respect to the seasonal flu or H1N1, suggesting restricted visitation to resident identified visitors or next-of-kin necessary for their care and well-being, acknowledging the essential care FCGs provide.⁽²¹⁾

The current study is part of a larger parent study that examined the impact of COVID-19 on FCGs providing care for PLWD across the caregiving continuum (home, supportive living, and LTC). The aim of this current study is to examine the impact of the restricted LTC access policies on FCGs and the PLWD they care for during the initial wave of the COVID-19 pandemic. Results from this study will provide evidence to inform policy regarding LTC access during subsequent waves of the ongoing COVID-19 pandemic, as well as in future public health emergencies.

METHODS

A Community Advisory Committee (CAC) was convened with our community partners, the Alzheimer Society of Calgary and the Dementia Network Calgary, and with family caregivers, to guide this mixed methods study. The CAC provided the research team with input and direction on survey design and implementation, focus group guides, and interpretation of the final results. Research ethics approval for this study was attained from the University of Calgary Research Ethics Board (REB20-0855).

Participants

Informed consent was obtained from all study participants. Survey participants were provided with a consent form and were required to check “yes” to having read and understood it before completing the survey. A separate consent form was e-mailed to focus group participants. Participant eligibility included FCGs over the age of 18 providing care for a PLWD in LTC. Study participants were recruited through the FCG networks of community partners. A total of $n=70$ participated in the survey, with seven participating in the follow-up focus groups.

Data Collection

An online survey with multiple choice and open-ended questions was conducted in June/July 2020 with FCGs for PLWD residing in LTC. The survey link was distributed through our community partners using electronic newsletters, organization web pages, and social media pages. In September 2020, participants who agreed to study follow-up were invited to participate in focus group discussions about their caregiving experience during the COVID-19 pandemic. Focus groups were conducted with a total of $n=7$ participants. The focus groups were 60–90 min and run by a research associate with expertise in focus group facilitation. Focus group guides were

developed in advance in consultation with the CAC to further contextualize survey results. Focus groups were conducted virtually using Zoom Video Communications and audio recorded. The audio recordings were transcribed verbatim with identifiable information removed.

Analysis

Descriptive statistics of quantitative data were obtained using IBM SPSS Statistics version 26 (IBM SPSS Statistics, Armonk, NY). Long answer survey questions and focus group transcriptions were qualitatively analyzed using thematic analysis in NVivo version 12 (QSR International, Melbourne, Australia). Thematic analysis identifies themes in the data that are analyzed within the context of the text, as well as within a coding framework.⁽²²⁾ The focus group transcriptions and long-answer survey questions were inductively coded by two independent researchers, and any coding differences were discussed and amended based on consensus, with kappa coefficients >0.61 indicating substantial agreement.⁽²³⁾

RESULTS

Demographics

Seventy FCGs for PLWD in LTC participated in the study. The average age of FCGs was 59 years old, with 76% identifying as women. The average age of the PLWD for whom they care was 76 years old, with 67% identifying as women. FCGs were a child/child-in-law (50%), spouse (39%) or other relative (11%). The majority (60%) of FCGs had provided care for their PLWD for over four years.

Four major themes emerged as the key areas of concern for the FCGs, as follows.

1. FCGs Need Continued LTC Access to Provide Essential Care to PLWD

FCGs (46%) who participated in the survey felt access restrictions in LTC went beyond what was necessary during the first wave of the COVID-19 pandemic. The restrictions made it difficult, if not impossible, for the majority of FCGs (83%) to maintain the level of care they had been providing prior to the COVID-19 pandemic. FCGs were concerned over the ability of already busy staff to provide the level of personalized care FCGs provided prior to COVID-19. FCGs expressed their frustration about the lack of personalized care:

“... an example would be my mother hoards, so I would be in there every week and I'd clean stuff out right. Of course, now because of COVID you can't do that, and the staff can't do that because they're busy, they're trying to do other things. So, there was a lot of frustration not being able to do those pieces of care that you were doing before.”

FCGs expressed concern around ‘adequate care’ not being provided and the ‘quality of institutional care.’ While FCGs expressed gratitude toward the staff in their efforts to provide care during the challenges of COVID-19, they worried about the lack of personalized care for their PLWD. FCGs described

the decline they observed in PLWD, speculating that it was a result of decreased care during the COVID-19 pandemic, with one FCG stating:

“I don’t know that they were ever getting enough care, personal care. The nursing home that my mom is at is excellent... But, with COVID ... their personal care has decreased. I’ve seen other patients who do not have the personal care, they’ve lost weight, they’ve stopped eating, they’ve stopped communicating. It’s just so sad to see what COVID has done to senior care in nursing homes. It’s very sad.”

2. Alternative Communication Strategies Are Not Always Effective for PLWD and Their FCGs

While no outside visitors were able to enter LTC facilities during the initial months of the COVID-19 pandemic, alternate communication methods were made available to facilitate contact between PLWD and their FCGs. Of the FCGs who completed the survey, video calls were the most common method utilized (67%), followed by outdoor visits (66%), and phone calls (49%). Unfortunately, of those who used these methods, around a quarter found them ineffective (28%, 20%, and 32%, respectively). While some (36%) FCGs discussed being able to communicate with their PLWD using these methods as a positive experience, focus group participants expanded on their limitations. They pointed out the difficulty of using technology that was inaccessible to their PLWD, and how the facilities were not adequately set up to support these modes of communication, with unstable internet connections or no access to quiet spaces. In addition, many PLWD have trouble focusing, and have visual or hearing impairments making telephone or video calls difficult, as one FCG shared:

“... my mom, she’s 90 percent deaf so she can’t hear the best of times, but because of the dementia she thought she was looking at a video of me and my family. So, she wasn’t communicating with us at all. It didn’t matter how many questions I asked, I even had the caregiver there trying to engage her, she just did not understand this technology. So, sadly those types of visits were not helpful at all for us.”

Another communication barrier FCGs discussed was with LTC facility staff. FCGs were frustrated by variable communication with staff and challenges in receiving information about their PLWD, with one FCG recalling:

“I still didn’t get the personal information that I wanted about my mom from the staff about how she’s doing. [The] most I would get was ‘oh she’s doing fine today, she’s being cooperative’....”

FCGs did recognize the often-extreme constraints that LTC staff were operating under, with many FCGs (44%) expressing their ‘gratitude to others’ during the pandemic, specifically LTC staff:

“The care home he is in is AMAZING!!...Staff keep families up to date with the latest scientific, medical,

and policy information with weekly updates. They made changes in how they operated to ensure residents still had contact with family...My dad was shaved, well dressed, and recently had a haircut when I did my first window visit in June. ...I had so little to worry about his care because the staff and the administration care about the residents.”

3. Restricted Access in LTC Facilities Has a Negative Impact on FCGs and PLWD

The majority (96%) of FCGs reported that access restrictions to LTC facilities had a negative impact on them. FCGs reported feeling higher levels of social isolation (66%) and strain (63%), and reduced quality of life (57%) since the COVID-19 pandemic began. These negative outcomes are highlighted by one FCG sharing what he missed the most during the COVID-19 pandemic:

“With my wife in LTC, I have missed being able to be with her. Seeing her every day gave me a sense of purpose and commitment. That has been taken away and replaced with worry and anxiety.”

The risk/benefit analysis of negative impacts from social isolation compared to COVID-19 infection was contemplated by FCGs with one FCG sharing:

“Biggest worry—it started out being that they might get COVID. Now, it’s that they will go nuts...They fear isolation more than COVID.”

FCGs acknowledged the need for restrictions to protect residents in LTC facilities, but felt conflicted about the detrimental effect of these restrictions on their PLWD’s well-being. One FCG reflected:

“I mean I’m really hard pressed to see how her decline isn’t somewhat correlated to those kinds of restrictions that ended up being in place. So, whether I feel really good about how the care facility has managed to control COVID, I also am worried that those restrictions have exacerbated her decline.”

FCGs noted dementia progression in the PLWD including cognitive, physical, and mental health decline. Of the FCGs who had knowledge of how the PLWD they care for was doing, 51% reported an increase in dementia-associated responsive behaviours since the pandemic began. One FCG described her observations:

“We lost that ability to go in and check in on my mom, of course she also, like everyone else, started to decline with the lack of contact. What happened was the facility started to see behaviour changes in her and to deal with it they medicated her. So, she was very medicated, she changed quite a bit.”

Studies have shown that use of antipsychotics to treat the responsive behaviours associated with dementia only have a modest effect improving symptoms and are often associated with adverse effects.⁽²⁴⁾ There are non-pharmacological

interventions that can be administered by FCGs which can significantly reduce the responsive behaviours of dementia without the adverse effects of antipsychotics and should be considered as a first option.⁽²⁵⁾

4. FCGs Are Willing to Take Appropriate Action to Minimize COVID-19 Infection Risk

The biggest worry of FCGs (71%) was the ability to ‘maintain health’ during the pandemic, both for themselves and the PLWD in LTC. FCGs were concerned about preventing the spread of COVID-19 to facilities, and missing the ability to have ‘face to face contact’ (96%) and ‘eyes-on-care’ with their PLWD in LTC. Given the conflicting concerns for protecting their PLWD from COVID-19 infection while ensuring adequate care and social contact, FCGs were willing (84%) to undergo necessary training in personal protective equipment and infection control procedures to ensure access while mitigating risk as evidenced by the following:

“I was hearing Dr. XXXXXX and so on saying that people with dementia how difficult it is for them not having any of this contact. I had been an essential worker and I had sent a memo to the administrator, I said ‘look I’m available, I could go in...”

DISCUSSION & CONCLUSION

The COVID-19 pandemic has highlighted pre-existing issues within the Canadian LTC system^(1,5,11,13) while, at the same time, presenting a unique opportunity to address the problems. This study contributes to this opportunity by examining the challenges of LTC restricted access during the first wave of COVID-19 pandemic from the FCG perspective.

Although restricted access to LTC facilities in the early months of the COVID-19 pandemic was intended to protect the residents, there is mounting evidence of unintended negative consequences.^(1,5,11,13,15) When considering the impact of restricted access policies for PLWD in LTC, this study presents several key points regarding the necessary role of FCGs: 1) FCGs are providing essential care; 2) in-person engagement is required for many PLWD; 3) isolating PLWD from the FCGs results in negative outcomes for both members of the caregiving dyad; and 4) FCGs are willing to do what is necessary to mitigate infection risks while providing essential care.

A common theme discussed by study participants is variability of care being provided in LTC facilities, resulting in the need for many FCGs to remain involved in PLWD everyday care. The COVID-19 pandemic has demonstrated that an FCG’s role does not shift from care provider to visitor once someone is placed in LTC. There are 2,039 LTC facilities in Canada, with 46% being publicly owned and 54% privately owned.⁽²⁶⁾ Since LTC facilities are not part of the *Canada Health Act*, there is no requirement for public funding and, therefore, no consistent oversight between provinces.⁽²⁷⁾ It is under provincial health authorities’ jurisdiction to apply policies, if any, to LTC facilities. Lack of structured regulation

has contributed to variation in quality of care and the issues with Canada’s LTC system.⁽⁵⁾ Regulatory oversight of care standards, care staff (including training requirements), and reporting would support improvements for quality of care in LTC facilities.

FCGs are essential partners in care provision, providing hands-on care and supporting emotional, mental, and physical health, as well as social engagement for PLWD in LTC.⁽¹⁰⁾ Although many LTC facilities have tried to facilitate FCGs of offering this support during COVID-19 through alternative communication methods, these methods are not suitable for many PLWD and should not be viewed as a sufficient alternative to in-person care. PLWD have faced the negative consequences of being socially isolated as a result of being separated from their FCGs. FCGs have also experienced adverse outcomes due to the COVID-19 pandemic health measures, while being concerned about the quality of care for their family member with dementia in LTC. Studies have shown that FCGs face adverse physical and mental health outcomes in their role as caregivers, but that outcomes for FCGs improve when they are involved in providing care.^(16-20,28-30)

This study provides evidence of the importance of FCGs providing in-person care to PLWD in LTC, as providing care remains an important part of their role as a FCG. Despite competing priorities, FCGs are committed to their caregiving role, with the overwhelming majority of FCGs reporting that they are willing to spend the time to get additional training to ensure safe, continued, in-person access to the PLWD in LTC. The COVID-19 pandemic is an ongoing threat to PLWD in LTC facilities who face increased severe infection risks, as well as the potential of being separated from their FCG in order to minimize risk of exposure. This study shows that keeping FCGs out of LTC should not be an option going forward. We cannot look at access to LTC as dichotomous: either closing the doors to protect residents from COVID-19 infection OR granting FCGs access to provide essential care. Instead, FCGs should be supported with the necessary equipment, training, and protocols required to mitigate infection risk while they continue to provide essential care to PLWD. FCGs are key care partners for PLWD and should be recognized as such.

“It is informally now accepted, the importance of family caregivers... For the families to stay involved, like it’s you know life and death care that we’re giving. So, it’s got to... continue in some way, whatever that looks like. But it should never be the first option to just shut everything off because, like I said, it’s literally life and death.” Family Caregiver

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CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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