Caring for Caregivers

Data Report for Calgary Pilot Study Summer 2020:

The Impact of COVID-19 on Family Caregivers for Persons Living with Dementia

Report Prepared for Alzheimer Society of Calgary

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The Impact of COVID-19 on Family Caregivers for Persons Living with Dementia

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Executive Summary

COVID-19 public health measures have led to considerable changes in care provision for people living with dementia (PLWD) across the settings in the care continuum, resulting in the need for family caregivers (FCGs) to significantly adapt their caregiving routine to accommodate these ongoing changes. FCGs for PLWD in the community are faced with managing these changes with limited access to supportive care resources and services like homecare and adult day programs. FCGs for PLWD in assisted/supportive living and long-term care have been restricted in their ability to participate in care provision due to strict no-visitor policies that are meant to minimize infection in congregate housing settings.

Our research team explored the experiences of Albertan FCGs for PLWD. The purpose of this study was to examine the impact of the COVID-19 pandemic on FCGs' knowledge about the pandemic, their ability to provide care for and /or visit family members, and the effect of pandemic-related public health messaging and measures on FCG and PLWD outcomes. Results of this study have been used to develop recommendations for provincial health authorities, provincial stakeholders, and dementia support agencies on how to best support FCGs for PLWD during the ongoing COVID-19 pandemic as well as for future public health emergency planning such as the second wave of COVID-19 in our province and across the country.

A total of 230 FCGs completed the survey with 50% caring for a PLWD at home in the community, 18% caring for a PLWD in an assisted/supported living facility and 32% caring for a PLWD in a long-term care facility. The survey also included open-ended questions in which FCGs were asked about what they were missing most, and their biggest worries during the COVID-19 pandemic. Responses indicate important differences in the worries and needs of FCGs across care settings.

The findings of this research have shown that our Alberta FCGs have reported a significant increase in caregiving responsibility, they are overburdened, and many of the PLWD have experienced a decline in their wellness and function as a result of pandemic-related public health measures. Most concerning, FCGs have explicitly stated they are struggling with their isolation and their need for greater support in their role as caregiver for PLWD. As COVID-19 cases continue to rise, FCGs and PLWD must be considered when new or revised public health measures are drafted. Based on the findings of this study, we have proposed the following recommendations to the Government of Alberta: 1) Caregiving support; 2) Clear, correct and concise information; and 3) Continued access to care recipients.

Background

Dementia is a common chronic health condition among older adults impacting 7.1% of Canadians over the age of 65[3]. Dementia is characterized by progressive cognitive impairment that interferes with daily life[4]. Therefore, as the disease advances, PLWD become increasing reliant on FCGs. We are defining a FCG, sometimes called an informal caregiver, as an unpaid individual (e.g. a spouse, partner, family member, friend, or neighbor) involved in assisting the PLWD with activities of daily living and/or everyday tasks. Care provision is a complex and variable role requiring multidimensional support that extends across physical, psychological, spiritual, and emotional domains[5]. Despite the complexity of the role and potential negative outcomes, FCGs are often providing care without adequate or affordable resources and support services. Typically, FCGs are responsible for providing both emotional and physical care as well as organizing and coordinating health services on behalf of the PLWD[6]. As the disease progresses, PLWD become more dependent upon their FCG to assist with even the basic activities of daily living, which increases the stress of caregiving and negatively affects the health of the FCG, further reducing their ability to support the PLWD[7]. FCGs often operate at the limits of their abilities juggling the pressures and commitments of their own lives, family and work while also providing increasing amounts of care for PLWD[8].

As of November 9th, 2020, there have been 268,735 confirmed COVID-19 cases in Canada[9]. Older Canadians over the age of 60 now account for 24% of the COVID-19 cases yet they also account for 97 % of the deaths, 70% of the hospitalizations, and 63% of ICU admissions. In Alberta, 34,873 cases have been confirmed with those over 60 years or 14% of all cases. Albertans over 60 years of age account for 59% of hospitalizations, 60% of ICU admissions, and 96% of deaths. To date, 82% of the total deaths from the COVID-19 pandemic have been linked to long-term care facilities[10]. Moreover, adults 65 and older with chronic conditions, such as dementia, are at even higher risk of mortality[11]. Of those residing in long-term care facilities, 69% have a formal diagnosis of dementia and this reflects a double jeopardy for PLWD and increases the challenges for the FCGs who continue to be instrumental in their care. FCGs whose family member with dementia resides in the community are equally challenged by COVID-19, as 70-80% of their care is provided by a FCG[12]. Regardless of where the PLWD resides, FCGs are key partners in their care provision. Although the caregiving role has positive aspects, the negative impacts the role has on FCGs physical and mental health, social relationships, and employment and financial well-being are well documented as they work to ensure the safety and comfort for the PLWD[5-11]. Negative FCG outcomes have only been exacerbated by the current COVID-19 pandemic and these risks and challenges are shared by FCGs for PLWD across settings in the care continuum.

As such, our research team explored the experiences of Albertan FCGs for PLWD. Results of this study have been used to develop recommendations for provincial health authorities, provincial stakeholders, and dementia support agencies on how to best support FCGs for PLWD during the ongoing COVID-19 pandemic as well as for future public health emergency planning such as the second wave of COVID-19 in our province and across the country.

Study Design

In partnership with our community partners, the Alzheimer Society of Calgary and the Dementia Network Calgary, a Community Advisory Committee (CAC) was convened to guide this study. The CAC was comprised of our partner organizations and FCGs for PLWD across the care continuum. The CAC provided the research team with input and direction through the survey design, focus group guides and with the interpretation of the final results. Research ethics approval for this study was attained from the University of Calgary Research Ethics Board (REB20-0855). This study was designed and lead by Dr. Gwen McGhan (Nursing, U/Calgary) and Dr. Deirdre McCaughey (Community Health Sciences, U/Calgary) and supported by research associates Dr. Whitney Hindmarch and Kristen Flemons (W21C, U/Calgary).

The purpose of this mixed methods study was to examine the impact of the COVID-19 pandemic on FCGs' knowledge about the pandemic, their ability to provide care for and /or visit family members, and the effect of pandemic-related public health messaging and measures on FCG and PLWD outcomes (see Figure 1 below). An online survey was conducted in June/July 2020 with Calgary area FCGs for PLWD who reside at home in the community, in assisted/supported living or in long-term care. A link to the survey was distributed through our community partners the Alzheimer Society of Calgary and the Dementia Network Calgary. The survey also included open-ended questions, in which FCGs were asked about what they were missing most and their biggest worries during the COVID-19 pandemic. In September 2020, survey participants who agreed to study follow-up were invited to take part in focus group discussions about their caregiving experience during the COVID-19 pandemic. The focus groups were designed to incorporate and explore the open-ended survey questions and create discussion prompts around the following topics related to caregiving for PLWD during the COVID-19 pandemic: 1) COVID-19 Knowledge, 2) COVID-19 Policies; 3) Provision of Care During COVID-19; and 4) Outcomes for FCGs and PLWD.

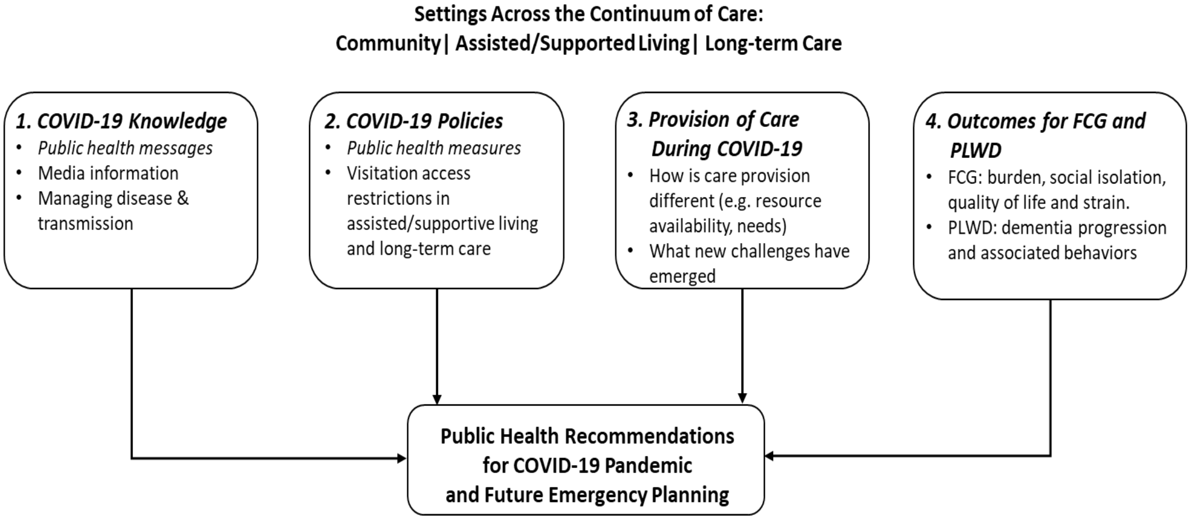


Figure 1: Care Provision Experiences During a Global Pandemic

Study Results

Demographics and Open-Ended Questions:

A total of 230 FCGs completed the survey with 50% caring for a PLWD at home in the community, 18% caring for a PLWD in an assisted/supported living facility and 32% caring for a PLWD in a long-term care facility. The average age of FGC survey respondents was 59 years old and the average age of the PLWD they care for was 75 years old. The majority, 77%, of FCG survey respondents were women and 61% of FCGs were providing care for a woman living with dementia. Almost half of the survey respondents (46%) were the spouse of the PLWD they care for, 41% were the child/child-in-law, 12% were other relatives and 1% were friends. Half (50%) of the FCGs that participated in the study have been providing care for a PLWD for more than 4 years with 27% reporting they spend more than 40 hours a week caregiving.

The survey also included open-ended questions, in which FCGs were asked about what they were missing most and their biggest worries during the COVID-19 pandemic. Responses to the questions indicate important differences in the worries and needs of FCGs across care settings. FCGs in all care settings identified inconsistency in how public health measures were being carried out by organizations that resulted in a lack of clarity in how public health measures were interpreted and executed by these organizations.. FCGs in the community indicated that an increase in social isolation and a lack of respite and supportive resources were negatively affecting their quality of life and ability to provide care. They also expressed concern over who would care for their PLWD if they were to become ill, with on FCG commenting: “If I get sick, what then?” In comparison, FCGs for PLWD in assisted/supportive living and long-term care noted extreme concern and anxiety over public health measures regarding access to PLWD in these facilities and were primarily concerned about missing time with their loved ones, quality of care being provided, and the impact that increased social isolation for the PLWD was having on the progression of their dementia. FCGs indicated they were missing regular face-to- face contact with their PLWD in long-term care.

COVID-19 Knowledge:

Accurate and clear public health messaging regarding COVID-19 and public health measures are critical to the successful delivery of information that can encourage helpful behaviours, ease a nervous public, and reduce the impact of events during a public health crisis[13]. Our study examined FCGs evaluation of COVID-19 related Alberta public health messaging, the sources of information they use, and their perceived COVID-19 related knowledge. Overall, the majority (64%) of FCGs rated COVID-19 Alberta public health messaging as good-excellent especially messaging around the disease spread (88%), symptoms (84%) and finding information (77%) related to COVID-19. However, areas where FCGs believe messaging could improve include information about what to expect in the future (49% rated as “*less than good*”) and caregiving information (70% rated as “*less than good*”).

The most frequently used media and information sources for COVID-19 knowledge by FCGs are television (78%), conversations among family/friends (66%) and websites (62%). FCGs over the age of 60 years old used more traditional sources of information such as television, newspaper and radio compared to FCGs under 60 years of age who utilize websites, search engines and social media comparatively more. Surprisingly, FCGs report very infrequent use of healthcare providers as COCID-19 information sources (79% reported occasional or never use).

Almost all FCGs (94%) rate their knowledge regarding COVID-19, how the virus spreads and how to protect themselves and the PLWD they care for, as good or excellent. Interestingly, FCGs who rated their own health as less than good or their quality of life as lower than usual during the COVID-19 pandemic also rated their overall COVID-19 related knowledge lower than FCGs that rated their own health and quality of life as good or unchanged respectively.

COVID-19 Policies:

The federal, provincial and local governments have implemented new policies and procedures to mitigate the spread of COVID-19. Although the intent of these new policies has been to protect people from the virus, they have also led to severe, unintended consequences for FCGs and the PLWD they care for. Most strikingly, the social distancing measures put in place have led to assisted/supported living and long-term care facility operators enacting restricted access policies and even complete facility lock outs. These extreme policies have resulted in the residents being separated from family members for extended periods of time, being isolated, experiencing poor quality of care or lacking essential care, and even dying alone[2,14,15].

"I would like to wear a face shield rather than a mask so that my mother (who has dementia and is profoundly deaf) can see my face and mouth."

Of the 70 FCGs who completed the survey and care for a PLWD in long-term care, 46% believe the restrictions in long-term care facilities go beyond what is needed with 97% reporting that the restrictions have negatively impacted them. The majority (84%) of long-term care FCGs are willing to undertake necessary training in personal protective equipment (PPE) and infection control procedures to ensure continued access to the PLWD they care for. An additional 13%, while willing to undergo such training, raise the important concern around PPE such as masks causing confusion in the PLWD as they would not be able to recognize the FCG or effectively communicate due to the PLWD being hearing impaired and heavily reliant on lip reading. One FCG shared that: "*I believe that if I were to wear a mask of any kind over my face, it would scare my mom if not confuse her even more as to who I am*". Another FCG stated: "*I would like to wear a face shield rather than a mask so that my mother (who has dementia and is profoundly deaf) can see my face and mouth*."

During periods of extreme restricted access, some long-term care facilities offered alternative visitation options including staff facilitated phone and video calls as well as outdoor visits. Of the long-term care FCGs in our study, 52% reported utilizing phone calls, 71% video calls and 69% outdoor visits and of those who were able to use these visitation methods, 32%, 28% and 20% found they were ineffective respectively. In focus groups, FCGs expressed their frustration with these communication methods with one FCG sharing her frustration with video calls: "… *it was very cruel, if there's anything to learn from this I think that would be the one big thing. What type of adjustments could have been made to accommodate something, anything other than video chats which mean nothing...*"

Provision of Care During COVID-19:

FCGs are essential care partners for PLWD across the care continuum including: the community; assisted/supportive living facilities; and long-term care. COVID-19 related policies have greatly impacted FCGs ability to maintain their usual care provision as a result of reduced access to caregiving support resources, limited access to PLWD in care facilities and restrictions on routine daily life[1,16]. Sixty-one percent of the FCGs in this study reported high levels of burden associated with the changes in care provision. This is evidenced by FCGs reporting a decline in supportive caregiving resource availability with an average of 5 resources being used prior to the COVID-19 pandemic to only 1.6 resources used during the pandemic. Some notable declines in resource utilization are transportation (100% reduction in use), day programs (97% reduction in use), legal services (87% reduction in use) endoflife planning (79% reduction in use), and support groups (67% reduction in use). In the focus groups FCGs repeatedly expressed how difficult providing care has been with the sudden decline in resource and support services. One FCG stated about the change of services: "*so everything that we had in place stopped, just stopped.*" FCGs in the community were left stranded at home with no help, with one FCG explaining: "*I'm not sure that the system evolved quick enough to help support caregivers, so I think there are more innovative ways that they could have pivoted… we have these people in homes, in the community, we need to figure out how do we continue to offer support at a low risk kind of a way.*"

> *"If you don't come and help, I'm done, I cannot do this anymore."*

Another significant change in the provision of care for FCGs is the amount of time spent with the PLWD for whom they care. There is a stark contrast between many FCGs living at home in the community who are now providing constant care to their PLWD, with no respite breaks due to no/severely reduced access to these resources, and FCGs caring for a PLWD in a care facility who have limited or no access to their family member. Of the FCGs providing care for a PLWD in the community, 33% are spending more time assisting with activities of daily living during the COVID-19 pandemic than they were before the pandemic began. In the focus groups, FCGs were emphatic about their need for respite, with one FCG sharing: "*if you don't come and help, I'm done, I cannot do this anymore.*" Many of the FCGs reported they were struggling to cope, for example one FCG said: "*it's a hard struggle all by yourself here, sometimes I just, I just want to run away and not do anything anymore. Cause I'm not young anymore either, so I want to just to have some time to myself….*" Some FCGs reported having to leave their job and assume more caregiving responsibilities, which further impacted their ability to have any respite, as exemplified by one FCG saying: "*it's been hard, I mean at least I had my work to go… I mean* *the only time I was ever alone was driving to [work] and driving back, and that's 12 minutes each way. Now I don't even have 12 minutes, and yeah it's very hard."*

> *"It's a hard struggle all by yourself here, sometimes I just, I just want to run away and not do anything anymore. Cause I'm not young anymore either, so I want to just to have some time to myself…."*

For FCGs of PLWD living in a facility, 90% report the time spent together was dramatically reduced, with most not having a clear sense of how the PLWD is doing. In focus groups FCGs spoke about the difficulty of getting information from staff, as one FCG reported "*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' and that's about it you know.*" Particularly when it came to decline, FCGs felt they were not receiving all the relevant information as staff had limited time to elaborate on their family member's condition. One FCG shared her concern with the following:

> *you know there was certainly a number of questions that I could tell people didn't want to answer and they sort of wandered away from, and I get it, it's hard to have those conversations. At the same time, if I only have five minutes with you guys in a week, I need to know what's going on. If my mom's lost ten pounds that's a thing. She was skinny as a rail to begin with so I don't see how she could have possibly lost ten pounds. I think the staff are doing their best but, I think we family have a certain expectation of, if we can't see our person, at least tell us how they're doing. They sent the odd photo and stuff like that but…for some of our weekly calls she'd be super dozy through the whole thing. So, it's like not having [visits] at all, and just that long time period of going by without really having any sense of how your person is doing.*

Moreover, FCGs pointed out that they had special knowledge of their PLWD's habits and needs that was necessary to provide adequate care. Staff at care facilities do not possess this individualized knowledge and may not be able to provide the same level of personalized care as exemplified in the following:

> *one of the and maybe the biggest, words is frustrating, being unable to monitor your loved one and make sure that things are going ok. So, like 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.*

These FCGs provide essential care to PLWD and therefore preventing them from accessing the PLWD to provide care should not be an option:

> *I know that it is informally now accepted as like understanding the importance of family caregivers. I mean there's lip service paid to it but if it doesn't translate into actual power, I'll say for the families to stay involved, like it's you know life and death care that we're*

> *giving. So, it's got to be I guess written down in that formula, to allow it to continue in some way, whatever that looks like. But it should never be the first option to just shut everything off because that is, like I said, it's literally life and death.*

Outcomes for FCG and PLWD:

Although there are many positive aspects of providing care to a family member with dementia, FCGs spend significant amounts of time providing care, often to the detriment of their own physical and mental well-being[17]. There is also evidence that the stress and negative health effects associated with caregiving can reduce the FCGs ability to support the PLWD, which can lead to premature institutionalization and unmet needs[7,18]. To address these issues, our study examined the impact of COVID-19 on the outcomes of both FCGs and PLWD.

"With my wife in long-term care, I have missed being able to be with her. Seeing her everyday gave me a sense of purpose and commitment. That has been taken away and replaced with worry and anxiety."

Overall, most (61%) FCGs report high levels of burden. FCGs caring for a PLWD in the community reported significantly higher levels of burden compared to those caring for a PLWD who resides in assisted/supportive living or long-term care. The FCGs providing care in the community may be experiencing higher levels of caregiver associated burden because they are providing increased hands-on care whereas those providing care for a PLWD in a care facility have restricted access. This finding was repeated in the focus groups with FGCs at home who highlighted how difficult it has been to maintain a balance between their everyday life and providing care. One FCG shared her high level of burden and stated: *"at this point the whole house is kind of in turmoil because all I do is look after mom, I don't have any energy to give anything else."*

The majority of all FCGs report that they feel more socially isolated (69%) as well as experiencing increased strain (66%) since the COVID-19 pandemic began. Additionally, 55% of FCGs report that their quality of life has been reduced. Focus group participants emphasized these themes as they spoke of experiencing distress and not knowing where to find support. A FCG said: *"you know sometimes I get so distressed; I don't know who I can talk to"*. Another negative outcome of the pandemic is that FCGs have been separated from their life-long partners. One husband shared: *"with my wife in long-term care, I have missed being able to be with her. Seeing her everyday gave me a sense of purpose and commitment. That has been taken away and replaced with worry and anxiety."*

> *"I really think the isolation broke her spirit, so yes she was on the decline and we probably would have lost her in the next year or two anyway, but this certainly pushed her down that slippery slope, I really think it did."*

Many (78%) FGCs reported a noticeable increase in one or more of the responsive behaviours associated with dementia (hallucinations, agitation, depression, anxiety, euphoria, apathy, etc.) since the COVID-19 pandemic began. In the focus groups, participants spoke about facilities not having the capacity to cope with the added workload due to COIVD-19 protection procedures, limited staffing to properly manage increasing functional decline in the PLWD and increases in responsive behaviours. One FCG expressed concern about the increased use of medication to address behaviour changes, "*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 behavior changes in her and to deal with it they medicated her. So, she was very medicated, she changed quite a bit."* Focus group participants with their PLWD in a facility stressed that the social isolation noticeably contributed to their family member's decline. One FCG described it this way: *"I really think the isolation broke her spirit, so yes she was on the decline and we probably would have lost her in the next year or two anyway, but this certainly pushed her down that slippery slope, I really think it did."* Likewise, PLWD in the community are also suffering from isolation because of widespread anxiety of spreading the virus as highlighted by a FCG: *"I have an aunt who's been isolated, she has really gone down very, very much so, so depressed, she just feels that her family doesn't even love her anymore… you know you've just isolated them in their room and [you're] gonna lose people just because of that, their hearts are broken."*

Conclusions

To mitigate the serious and often fatal effects of COVID-19 for older adults, our Provincial Health Ministry, like other Ministries across Canada, have enacted numerous COVID-19 public health measures. These measures have reduced/eliminated support services and resources for FCGs providing care for PLWD living in the community as well as measures resulting in reduced/eliminated visiting access to PLWD in assisted/supportive living and long-term care. While stringent visiting and resource services guidelines have recently been adjusted to allow for more support for FCGs, with the current increasing rates of COVID-19 this may once again be changed.

The findings of this research have shown that our Alberta FCGs have reported a significant increase in caregiving responsibility, they are overburdened, and many of the PLWD have experienced a decline in their wellness and function as a result of pandemic-related public health measures. Most concerning, FCGs have explicitly stated they are struggling with their isolation and their need for greater support in their role as caregiver for PLWD. As COVID-19 cases continue to rise, FCGs and PLWD must be considered when new or revised public health measures are drafted. Based on the findings of this study, we have proposed the following recommendations to the Government of Alberta:

1. ***Caregiving support***

   Caregiving support resources should be consistently available for FCGs to provide effective care. COVID-19 public health measures make support services difficult or not possible to offer. Regular check-ins by case managers and resource information updates would enable access to the services that are available.

2. ***Clear, correct and concise information***

   FCGs require more timely information about public health protocols to enable optimal care provision and resource access. For effective delivery of this specific information, it should be communicated through multiple media sources.

3. ***Continued access to care recipients***

   FCGs are not just visitors, they are essential care partners that provide necessary care for PLWD in supportive living facilities. They recognize the need for essential infection control procedures and are willing to take appropriate training to ensure continued access.

References

1 Hoffman, G. J., Webster, N. J. & Bynum, J. P. W. A Framework for Aging-Friendly Services and Supports in the Age of COVID-19. *J Aging Soc Policy* **32**, 450-459, doi:10.1080/08959420.2020.1771239 (2020).

2 Stall, N. M. *et al.* Finding the Right Balance: An Evidence-Informed Guidance Document to Support the Re-Opening of Canadian Nursing Homes to Family Caregivers and Visitors during the Coronavirus Disease 2019 Pandemic. *J Am Med Dir Assoc* **21**, 1365-1370 e1367, doi:10.1016/j.jamda.2020.07.038 (2020).

3 Public Health Agency of Canada. Dementia in Canada, Including Alzheimer's Disease: Highlights from the Canadian Chronic Disease Surveillance System. (Public Health Agency of Canada, https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/dementia-highlights-canadian-chronic-disease-surveillance/dementia-highlights-canadian-chronic-disease-surveillance.pdf, 2017).

4 Alzheimer's Association. *What is Dementia*, 2020).

5 Honea, N. J. *et al.* Putting Evidence Into Practice®: Nursing Assessment and Interventions to Reduce Family Caregiver Strain and Burden. *Clinical journal of oncology nursing* **12** (2008).

6 Stajduhar, K. I., Martin, W. L., Barwich, D. & Fyles, G. Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nurs* **31**, 77-85, doi:10.1097/01.NCC.0000305686.36637.b5 (2008).

7 Kolanowski, A. *et al.* Determinants of behavioral and psychological symptoms of dementia: A scoping review of the evidence. *Nurs Outlook* **65**, 515-529, doi:10.1016/j.outlook.2017.06.006 (2017).

8 Sinha, M. Portrait of caregivers. (Statistics Canada, https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.pdf, 2012).

9 Government of Canada. *Coronavirus disease 2019 (COVID-19): Epidemiology update*, 2020).

10 Public Health Agency of Canada. COVID-19 in Canada: Using data and modelling to inform public health action. (Public Health Agency of Canada, https://www.canada.ca/en/public-health/services/publications/diseases-conditions/covid-19-using-data-modelling-inform-public-health-action.html, 2020).

11 Bianchetti, A. *et al.* Clinical Presentation of COVID19 in Dementia Patients. *J Nutr Health Aging* **24**, 560-562, doi:10.1007/s12603-020-1389-1 (2020).

12 Health Council of Canada. Progress report 2012 Health care renewal in Canada. (Health Council of Canada, https://healthcouncilcanada.ca/files/ProgressReport2012_FINAL_EN.pdf, 2012).

13 World Health Organization. Effective Media Communication during Public Health Emergencies. (World Health Organization, https://www.who.int/csr/resources/publications/WHO_CDS_2005_31/en/, 2005).

14 Estabrooks, C. A. *et al.* Restoring trust: COVID-19 and the future of long-term care. . (Royal Society of Canada, https://rsc-src.ca/sites/default/files/LTC%20PB%20%2B%20ES_EN.pdf, 2020).

15 Canadian Foundation for Healthcare Improvement. Better Together: Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19. (https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/bt-re-integration-of-family-caregivers-as-essential-partners-covid-19-e.pdf, 2020).

16 Chu, C. H., Donato-Woodger, S. & Dainton, C. J. (Wiley Online Library, 2020).

17 Canadian Institute for Health Information. Dementia in Canada. (Canadian Institute of Health Information, https://www.cihi.ca/en/dementia-in-canada, 2018).

18 Toot, S., Swinson, T., Devine, M., Challis, D. & Orrell, M. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatr* **29**, 195-208, doi:10.1017/S1041610216001654 (2017).

Impact of COVID-19 on Family Caregivers of People Living with Dementia

Calgary Pilot Study

June-September, 2020

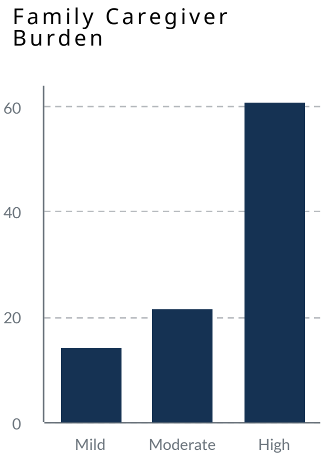
Survey Responses
230

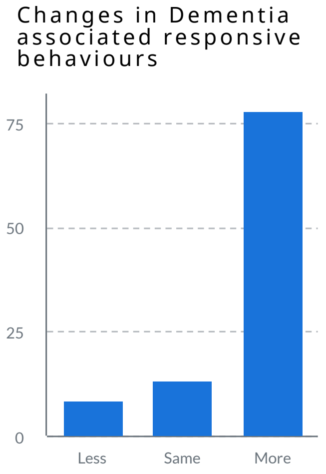
Person with dementia resides
Home 50.2%
Assisted living 17.5%
Long-term care 32.3%

Family caregiver relationship
Spouse 46.1%
Child/child-in-law 40.6%
Friend/relative 13.4%

Family caregiver gender
Women 77.8%
Men 21.8%

Outcomes of COVID-19 Public Health Measures

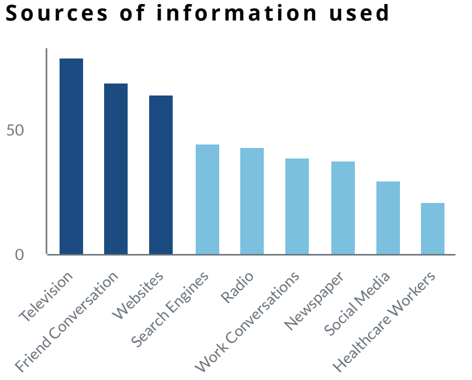

Family Caregiver Burden


Changes in Dementia associated responsive behaviours

Decline in Resource Utilization During the Pandemic

Overall	Day Programs	End of Life Planning	Support Groups
Average 5 ➡ 1.6 -68% Resources Used	0.9% -95.6%	8.3% -79.3%	12% -66.6%

COVID-19 Information


Sources of information used

Alberta Public Health Messaging
64% **Rated well**

Available Caregiving Information
67% **Needs Improvement**

Managing Care

All family caregivers

70%

Report significant changes in time spent with their person living with dementia

Long-term care family caregivers

46%

Believe long-term care restrictions go beyond what is needed

Home-based family caregivers

32%

Are providing more care associated with activities of daily living

> *"[My biggest worry is] that this will last longer than I can manage at home, alone, isolated."*

Alzheimer Society CALGARY 30+ years

Dementia Network CALGARY

UNIVERSITY OF CALGARY

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REB20-0855

Caring for Caregivers

Recommendations for supporting Alberta family caregivers for people living with dementia in a pandemic

BACKGROUND

Over 42,000 Albertans have a dementia diagnosis making family caregivers (FCGs) for persons living with dementia (PLWD) a valuable yet under recognized health care asset. They provide physically demanding, emotionally exhausting and time-consuming unpaid care to a vulnerable population. FCGs for PLWD are being confronted with considerable new challenges in the face of COVID-19 which has drastically altered their caregiving role.

RESEARCH STUDY

University of Calgary researchers Dr. Gwen McGhan and Dr. Deirdre McCaughey recently completed a study to examine the caregiving experiences of FCGs for PLWD during the COVID-19 pandemic. The online survey and follow-up focus groups were conducted June through September 2020. Pandemic related public health measures have required FCGs to adapt to new care routines with very limited supportive care resources and services available to them. They require more information on how to continue providing care under these new circumstances and are experiencing high levels of burden, social isolation, and strain, as well as reduced quality of life as a result. Based on our research, we recommend the following actions be enacted in Alberta to better support FCGs for PLWD in their caregiving roles and ultimately minimize decline in PLWD and reduce FCG burden.

RECOMMENDATIONS

1. Caregiving support

Caregiving support resources should be consistently available for FCGs to provide effective care. COVID-19 public health measures make support services difficult or not possible to offer. Regular check-ins by case managers and resource information updates would enable access to the services that are available.

2. Clear, correct and concise information

FCGs require more timely information about public health protocols to enable optimal care provision and resource access. For effective delivery of this specific information, it should be communicated through multiple media sources.

3. Continued access to care recipients

FCGs are not just visitors, they are essential care partners that provide necessary care for PLWD in supportive living facilities. They recognize the need for essential infection control procedures and are willing to take appropriate training to ensure continued access.

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The Impact of COVID-19 on Family Caregivers of People Living with Dementia: A Reseach Study

Public Health Messaging

Study Population

230 **Calgary area Family Caregivers**

Study Survey

(Conducted June-July 2020)

The survey was distributed using an anonymous website link to Calgary area family caregivers of people living with dementia across the care continuum (living at home in the community, in assisted living and in long-term care).

Background

Those most at risk from COVID-19 infection are older adults, especially those with chronic conditions like dementia. People living with dementia rely heavily on family caregivers for day to day care. It is therefore important that these caregivers are well supported and have all the information they need to continue caring for this vulnerable population.

Research Goal

To investigate the public health information needs of family caregivers related to COVID-19 and caring for someone with dementia during the pandemic.

Sources of Information

Used Frequently

Television
73%
Use Daily or More

Websites
48%
Use Daily or More

Friends & Family
35%
Use Daily or More

Used Rarely

- **Healthcare Providers**
  79% Use Occasionally or Never
- **Social Media**
  70% Use Occasionally or Never
- **Radio**
  70% Use Occasionally or Never

FINDINGS

RATED WELL

- The majority of family caregivers rate COVID-19 **Alberta Public Health messaging** high (64% rate overall messaging as good or excellent).
- Family caregivers are confident in their **COVID-19 related knowledge** (94% rate their knowledge of COVID-19, its spread and protection measures as good or excellent).

NEEDS IMPROVEMENT

- Family caregivers need more information about **what to expect in the future** (48% rate messaging on future expectations as less than good).
- Family caregivers need more information on **available services** and **providing care** during the pandemic (58% and 67%respectively rate available information on this as less than good).

Most Needed Information

Providing Dementia Care During the Pandemic
58%

COVID-19 Vaccine Progress
62%

COVID-19 Treatment Options
58%

"What is the next stage of care, when will it need to occur, and how to I get the assistance and advice I need to make those decisions?
I feel I have lost the love I once had as I don't even know this person anymore."

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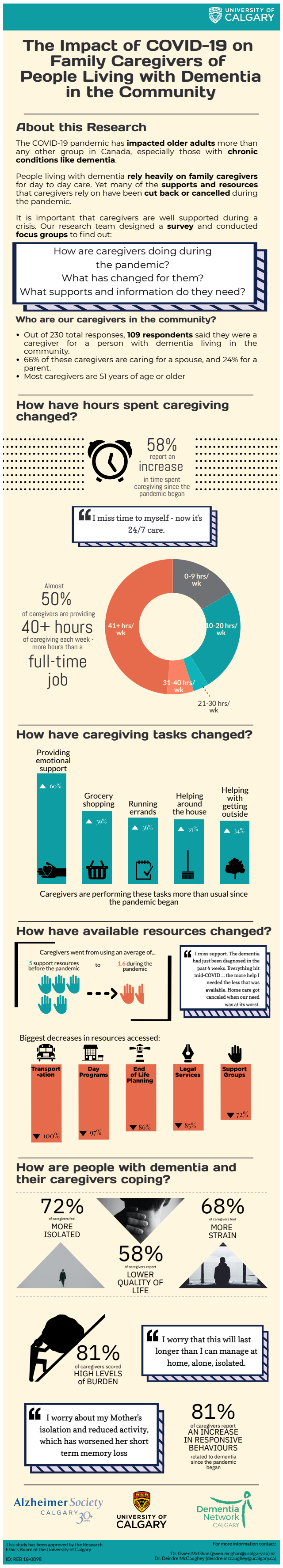
University of Calgary
Study REB20-0855



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The Impact of COVID-19 on Family Caregivers of People Living with Dementia in the Community

About this Research

The COVID-19 pandemic has **impacted older adults** more than any other group in Canada, especially those with **chronic conditions like dementia**.

People living with dementia **rely heavily on family caregivers** for day to day care. Yet many of the **supports and resources** that caregivers rely on have been **cut back or cancelled** during the pandemic.

It is important that caregivers are well supported during a crisis. Our research team designed a **survey** and conducted **focus groups** to find out:

How are caregivers doing during the pandemic?
What has changed for them?
What supports and information do they need?

Who are our caregivers in the community?

- Out of 230 total responses, **109 respondents** said they were a caregiver for a person with dementia living in the community.
- 66% of these caregivers are caring for a spouse, and 24% for a parent.
- Most caregivers are 51 years of age or older

How have hours spent caregiving changed?

58% report an increase in time spent caregiving since the pandemic began

> I miss time to myself - now it's 24/7 care.

Almost 50% of caregivers are providing 40+ hours of caregiving each week - more hours than a full-time job

How have caregiving tasks changed?

Caregivers are performing these tasks more than usual since the pandemic began

How have available resources changed?

Caregivers went from using an average of...

5 support resources before the pandemic to 1.6 during the pandemic

> I miss support. The dementia had just been diagnosed in the past 4 weeks. Everything hit mid-COVID ... the more help I needed the less that was available. Home care got canceled when our need was at its worst.

Biggest decreases in resources accessed:

How are people with dementia and their caregivers coping?

72% of caregivers feel MORE ISOLATED

58% of caregivers report LOWER QUALITY OF LIFE

68% of caregivers feel MORE STRAIN

81% of caregivers scored HIGH LEVELS of BURDEN

> I worry that this will last longer than I can manage at home, alone, isolated.

> I worry about my Mother's isolation and reduced activity, which has worsened her short term memory loss

81% of caregivers report AN INCREASE IN RESPONSIVE BEHAVIOURS related to dementia since the pandemic began

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This study has been approved by the Research Ethics Board of the University of Calgary

ID: REB 18-0098

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