

Family Caregiving for People Living With Dementia During COVID-19: A Thematic Analysis

Journal of Family Nursing
2022, Vol. 28(3) 219–230
© The Author(s) 2022



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/10748407221100553
journals.sagepub.com/home/jfn



Kristin Flemons, MA¹ , Gwen McGhan, PhD, RN, GNC(c)¹,
and Deirdre McCaughey, PhD, MBA, BMR(PT)¹

Abstract

This study examines the experiences and needs of family caregivers (FCGs) for people living with dementia (PLWD) during the coronavirus disease 2019 (COVID-19) pandemic. Six focus groups were conducted with 21 FCGs from across the care continuum and thematic analysis was used to illuminate FCGs descriptions of their experiences and needs. Three main themes were identified that highlight the disruption the pandemic caused for FCGs: changes in the caregiving role, information use and needs, and mental and physical health outcomes. To better support FCGs during COVID-19 and future public health emergencies, we recommend that (a) information is accessible, specific, and centralized; (b) resources are tailored to the caregiving dyad (FCG and PLWD) and creatively adapted to public health restrictions; and (c) opportunities for the caregiving dyad to receive physical, social, and emotional engagement and support are maintained.

Keywords

family caregivers, dementia, COVID-19, public health restrictions

For family and friend caregivers (FCGs)¹ of people living with dementia (PLWD), the coronavirus disease 2019 (COVID-19) pandemic has impacted almost every dimension of their lives and caregiving routines (Greenberg et al., 2020; Stall et al., 2020; Tsapanou et al., 2021). In addition to managing the risk of illness for both themselves and the PLWD, FCGs have had to navigate public health restrictions implemented to contain the pandemic—such as business closures, cessation of long-term care (LTC) visits, limitations on social gatherings, masking, and distancing—that have curtailed or closed many of the supports and resources FCGs relied on to maintain their caregiving routines (Hoffman et al., 2020). This is true for FCGs across the “caregiving continuum,” which encompass FCGs caring for a PLWD in the community (in the home of the caregiver or the PLWD’s own private residence), FCGs caring for a PLWD in continuing care (including assisted or supportive living and LTC), and FCGs who live at a distance from the PLWD.

Dementia is a disabling, costly, and challenging disease that affects more than 564,000 Canadians (Chambers et al., 2016) and approximately 51 million people worldwide (Institute for Health Metrics and Evaluation, 2019; World Health Organization, 2020). More than 90% of PLWD experience responsive behaviors, including apathy, depression, sleep disruptions, wandering, and anxiety, which contribute to declines in their physical and cognitive functioning, and

the quality of life of both members of the caregiving dyad (FCG and PLWD; Cerejeira et al., 2012; Kolanowski et al., 2017; Lyons & Lee, 2018). The progressive neurocognitive impairment that characterizes dementia means that, as the disease progresses, PLWD become increasingly reliant on their FCGs (Boscart et al., 2019). FCGs are thus a “critical national healthcare resource,” enabling the PLWD to remain in the community and/or providing essential care for the PLWD in congregate care settings (Harris, 2017; Romanow, 2002; Schulz & Sherwood, 2008).

In 2002, it was estimated that FCGs in Canada contribute Can\$25 billion annually in unpaid care (Family Caregiver Alliance, 2019; Hollander et al., 2009), while also incurring out-of-pocket expenses as a result of caregiving (Duncan et al., 2020). In Canada, there were 7.8 million FCGs in 2018, distributed across the caregiving continuum (Arriagada, 2020). Caregiving is a complex and often taxing role, which involves providing support across physical, psychological, spiritual, and emotional domains (Honea et al., 2008;

¹University of Calgary, Alberta, Canada

Corresponding Author:

Kristin Flemons, Research Associate, W21C Research and Innovation Centre, Cumming School of Medicine, University of Calgary, GD01, TRW Building, 3280 Hospital Drive N.W., Calgary, Alberta, Canada T2N 4Z6.
Email: kristin.flemons@ucalgary.ca

O'Rourke et al., 2003). Even before the pandemic, FCGs were often providing care without adequate resources or support, leading to stress, poor health outcomes, and reduced caregiving capacity (Kolanowski et al., 2017; Sinha, 2013). For example, Canadian FCGs provide an average of 26 hr of care per week for their family member with dementia and 45% of these caregivers experience significant distress (Canadian Institute for Health Information, 2016). In the spring of 2020, many caregiving supports were shuttered as public health restrictions were implemented across the country to limit the spread of COVID-19.

The ensuing months of the pandemic have overburdened FCGs across the care continuum (Greenberg et al., 2020; Stall et al., 2020; Tsapanou et al., 2021). Public health restrictions put in place to mitigate the spread of COVID-19 have rarely included adequate provisions or accommodations for FCGs, despite the critical care they provide—care that has often increased over the course of the pandemic (Keefe, 2020; Kent et al., 2020). To better support FCGs in their role as a “critical national healthcare resource,” an understanding of their experiences during the pandemic and their needs—both now and in future public health emergencies—is required. Creative adaptations and tailored support systems that can address the specific situations of this diverse community are likewise needed (Giebel et al., 2021).

To address this gap, we conducted a study to examine the impact of the COVID-19 pandemic on FCGs' ability to provide care and the effect of public health restrictions on the outcomes of both the FCG and PLWD. The larger study included an online survey, distributed to FCGs in spring/summer 2020, from which a smaller number were invited for further follow-up in a series of focus groups (Hindmarch et al., 2021; McGhan et al., 2022). This article reports the results from the eight follow-up focus groups conducted with FCGs across the care continuum, assessing the experiences, needs, and outcomes of FCGs of PLWD in a major Canadian city during the first wave of the pandemic, and provides recommendations based on their experiences. The experiences of FCGs during the first wave of the COVID-19 pandemic are instructive not only for considering or evaluating the initial public health response, but also in understanding how the difficulties encountered by FCGs were often caused by problems that preexisted the pandemic but were exacerbated to new extremes during the public health response. Similarly, the impact seen on quality of life for both FCGs and PLWD are ongoing and will have ramifications for caregiving dyads and the systems that support them for years to come.

Crucially, the experiences of the FCGs reported here highlight how the well-being of FCGs and PLWD are inextricably linked and how any successful public health intervention—whether to mitigate pandemic spread or support the caregiving dyad—must consider the dyad holistically and account for the diversity of their needs across the care continuum. Successful public health restrictions, information, and supportive resources must account for these unique

contexts and needs if they are to promote health while minimizing unintended consequences of restrictions.

Method

The parent study employed a sequential mixed-method design, consisting of an online survey distributed by our community partners (see the following), and follow-up focus groups with select participants. Ethical approval for the study was obtained from the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary (REB20-0855).

Community Advisory Committee (CAC)

Our study was guided at all stages by our CAC that consisted of representatives from local community-based organizations (Alzheimer's Society Calgary, Dementia Network Calgary), relevant academics and health system practitioners, and members of the study population (FCGs for PLWD across the care continuum). The CAC guided survey development, provided input on focus group discussion guides, and aided with the interpretation, validation, and dissemination of the study findings.

Data Collection

Inclusion criteria included FCGs above the age of 18 years providing care for a PLWD during the COVID-19 pandemic and the ability to communicate in English. An online survey was conducted in June and July of 2020 with FCGs for PLWD living in the community, in assisted and supportive living, and in LTC. A link to the survey was distributed through our community partners using electronic newsletters, organization web pages, and social media pages. Focus group participants were recruited from survey participants through a question that prompted participants to provide their email address if they were willing to participate in focus group follow-up.

Focus groups were conducted online using videoconferencing and teleconferencing software (Zoom) and were led by a member of the research team with qualitative training and expertise in focus group facilitation. We conducted eight focus groups early in September 2020, with between two and five participants in each (total participants = 21). Focus groups were divided along the caregiving continuum: three focus groups were conducted with FCGs in the community, one with FCGs for a PLWD living in assisted/supportive living, two with FCGs for a PLWD in LTC, and two with distanced FCGs.

Focus groups lasted from 60 to 90 min and were audio-recorded. Recordings were subsequently transcribed verbatim and de-identified. Participants were introduced to the researchers at the beginning of each focus group, the background and rationale for the study was described, and participants were given the chance to ask questions before recording

Table 1. Themes and Subthemes From Focus Groups.

Theme 1: Information use and needs	Theme 2: Impact on caregiving role	Theme 3: Outcomes
Subthemes	Subthemes	Subthemes
1. Adequacy of information	1. Care for the PLWD	1. FCG physical health
2. Predicting an uncertain future	2. Maintaining household(s)	2. FCG mental health

Note. PLWD = people living with dementia; FCG = family caregiver.

began. Due to the unique constraints of conducting qualitative research during the pandemic, participants were guided through a multistep informed consent process. Participants were first sent digital consent forms and provided informed, written consent through email. We then repeated the consent process at the beginning of each focus group to ensure full comprehension and obtained verbal consent before beginning session recordings.

Analysis

NVivo V12 data analysis software was used for qualitative data management. Using Braun and Clarke's method for inductive thematic analysis, the focus group transcripts were iteratively examined by two team members to identify concepts and compared for similarities and differences (Braun & Clarke, 2006; Nowell et al., 2017). Constantly moving back and forth within the data set allowed for the identification of initial codes. In the next phase, codes that were conceptually similar were grouped and organized hierarchically, forming the main themes within the data. The process was repeated until data saturation occurred and the themes are refined and named (Braun & Clarke, 2006). Trustworthiness of the data and analysis was ensured using the process outlined by Nowell et al. (2017) for ensuring credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility, dependability, and confirmability have been established both through prolonged engagement with the data and monthly triangulation and debriefing with our CAC. Their feedback was incorporated across the research design, data collection, and analysis phases. We believe that the descriptions of context and providing extended quotations from FCGs in their own words will aid readers in assessing the transferability of this study to their own contexts. Finally, the consolidated criteria for reporting qualitative research (COREQ) checklist was used as a guide for analyzing and interpreting the focus group results (Tong et al., 2007).

Results

Demographics

All of the 21 focus group participants were female, Caucasian, and highly educated, with 60% having completed an undergraduate or graduate degree, and the remaining participants having attended either a community/technical college or earned a professional designation. The

average age of participants was 63 years. Most cared for a PLWD between 71 and 80 years of age (40%) or 81 years or older (50%). A total of 55% of participants were caregivers for a parent or parent-in-law, 40% were caregivers for a spouse or partner, and 5% were caring for a sibling or other relative. The majority of participants had been caregiving for more than 4 years (53%) and spent 10 or 20 hr per week caregiving (42%) or more than 40 hr per week (32%).

Emerging Themes

A total of 35 codes were identified from participants' comments, which were subsequently reduced to three overarching themes and seven subthemes (Table 1). The overarching themes are (a) Information use and needs, (b) Changes in caregiving role, and (c) Outcomes (FCG and PLWD). Recommendations made by FCGs were also organized across these three themes (Table 2). FCGs' comments showed how the COVID-19 pandemic, and the subsequent public health restrictions, touched every aspect of the caregiving role and relationship.

Information use and needs. The first major theme identified by FCGs was *information use and needs*, which is divided into two subthemes: (a) *adequacy of information* and (b) *predicting an uncertain future*. FCGs expressed a desire for information that was specific to their circumstances; helped them in making decisions and risk assessments for daily activities; was uniformly applied by institutions, government, and health care organizations; and helped to alleviate the uncertainty that surrounded the pandemic and the public health response.

Adequacy of information. Despite a generally high level of trust in the information provided by the provincial government at the onset of the pandemic, FCGs expressed frustration with finding more granular information pertinent to their individual situations. For instance, one FCG expressed a desire for case numbers broken down to a neighborhood level to assess risk in completing daily errands:

So I did go to the [health region] website . . . to look at where the outbreaks [were] occurring in [province], which facilities and stuff like that . . . the map they have . . . I didn't find that very useful because it wasn't specific enough for me. Like [city], ok. . . but specifically where in [city]? (Participant No. 18, place on caregiving continuum: distance and assisted living)

Although more granular, location-based information did become available during the second and subsequent waves of the pandemic, its absence during the first wave left many FCGs feeling unsure about how to make decisions about safety and risk.

FCGs of PLWD living in continuing care also expressed their anxiety about finding information about the specific situations in continuing care facilities and their family member's safety:

They give just enough facts but not enough details. I understand that people that don't have a loved one in a nursing home maybe don't need to know exactly how many people have contracted COVID or are in isolation for COVID in that particular nursing home, but we who have loved ones in that nursing home should be given more details and should be provided more information. (Participant 14, long-term care)

The feeling that details (i.e., facility case counts, exposure events) were not forthcoming also contributed to decreasing levels of trust in the government communication and management strategy:

I think it's important if we're to trust our medical officers. . . that there be more forthcoming communication so that we can trust that our loved ones are being cared for in those times. It was very scary to hear about the numbers in the nursing homes but knowing that we probably weren't being given all of the information that they had on hand. That was very traumatic, I would say. (Participant 14, long-term care)

Dissatisfaction with inconsistency in information dissemination was compounded when FCGs reported that rules and regulations seemed to be open to interpretation, with different facilities enacting regulations in different ways:

For me it was confusing that [different care facilities] weren't [giving] the same information about lockdown procedures and visitation. . . they were both allowing visitation outside their buildings but in different manners. . . but I didn't understand why there was disparity between the two, the rulings around that. (Participant 3, community)

FCGs also expressed that little to no information had been made available to them about caregiving supports and ways to adapt their caregiving during COVID-19, leaving some to feel that they were "improvising" their care on their own during the pandemic. They emphasized that many of their peers did not know how to seek out this information on their own and did not know how or where to find support during the pandemic:

I would say that there really hasn't been any information about caregiving during COVID, and so I think that would probably fall into the bucket of "I don't know what I don't know." . . it's not to say that those resources don't exist, they might but I wasn't exposed to them in a way that [was helpful], . . . I think the information was pretty sparse. (Participant 19, distance and long-term care)

Predicting an uncertain future. FCGs expressed a strong desire for insight into how public health decisions and regulations would be made during the upcoming months, so that they could plan for their own needs and those of the PLWD. FCGs in the community, for instance, were worried about how regulations would impact home care and respite access, and how to plan care according to their own personal risk assessments:

What are the protocols going to be for our respite people, for our people coming to visit, are they going to be in our homes, and if so what are the restrictions, what do we have to do, can we go ahead and do it? Because these people are waiting too! And are . . . these people going to be going to five different places or they're going to be going two? Two in a day is ok I think but not five or six, and I think that's something we all need to have ASAP so that we can talk to our people and they can know what they're allowed to do, and we can go ahead with it. (Participant 6, community)

Similarly, FCGs for PLWD in continuing care wondered about visiting restrictions during the winter months:

What's going to happen next, what are we going to do in the winter and what's going to be available and how it's going to be available, and what are the protocols, and how do we manage? (Participant 13, assisted living)

FCGs agreed that, while concrete information was perhaps not always possible or realistic, a better understanding of *how* government and public health decisions would be made, and along which timelines and guideposts, would go a long way in enabling them to plan their own care and reducing the anxiety associated with uncertainty.

Overall, FCGs requested information that was accessible, consistent, specific to their situation and granular enough to be used for daily decision-making and risk assessment, addressed caregiving during the pandemic, and allowed them to plan for the future. Improving information clarity may have reduced some of the impact of the pandemic on FCGs' caregiving routine and levels of stress.

Impact on the caregiving role. The second key theme identified was the *impact of the pandemic on the caregiving role*. FCGs reported that the pandemic had radically altered many aspects of caregiving, including logistical, physical, and emotional facets. FCGs' descriptions of the impact of the pandemic on the caregiving role were divided into two main subthemes: (a) care for the PLWD and (b) maintaining their household(s).

Care for the PLWD. The subtheme of "care for the PLWD" encapsulates FCGs' experiences with providing direct, hands-on care for the PLWD and how this was impacted by the pandemic. Care may involve supporting activities of daily living (ADLs) and instrumental activities of daily living (IADLs). FCGs reported that managing care for the

PLWD during COVID-19 was more complex, stressful, and draining than before the pandemic, as access to resources was diminished and the risk of contracting the virus was at the forefront of their minds. FCGs' chief concerns were about monitoring the PLWD and ensuring that the PLWD was receiving adequate social stimulation.

Monitoring the PLWD. COVID-19 had a significant impact on FCGs' ability to monitor their family members. Monitoring had different meanings and implications depending on position on the caregiving continuum: for FCGs in the community, it involved preventing wandering and ensuring safety, whereas for FCGs in continuing care, monitoring generally involved being able to check in on the PLWD, ensure that ADLs and IADLs were being met, and provide any additional needed care or social stimulation.

For FCGs of PLWD in continuing care, the inability to simply "drop in" had far-reaching implications. One FCG explained their frustration at being unable to monitor the PLWD and make sure things were "going ok," with the following example:

My mother hoards, so I would be in [the LTC facility] every week and I'd clean stuff out. . . 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. (Participant 11, assisted living)

Other FCGs reported attempting to replicate the ability to "check in" on their family member through electronic devices and video calls. However, these methods highlighted areas of needed care—such as unwashed laundry or worsening hygiene—that FCGs were unable to assist with, leading to feelings of guilt and helplessness among FCGs.

FCGs for PLWD in the community highlighted the difficulty of balancing their caregiving responsibilities and monitoring their family member's well-being and safety. With many resources paused, such as care aides and day programs, FCGs had to rethink strategies for how to complete errands while ensuring adequate supervision for the PLWD. Previously routine activities were now charged with additional complexity and anxiety:

I did start going shopping when we were allowed to, and sometimes [husband] would come with me, or I take the risk of leaving him in the car but that's dangerous 'cause he could get out the car and [get] lost. (Participant 4, community)

Other FCGs recounted instances of their family member leaving home without their knowledge and the additional anxiety that COVID-19 caused:

And so she would actually take off, and when this was first starting I had the police out because I didn't know the severity of the situation, everybody was saying oh you know you just touch

somebody and you can get COVID, and it was so scary, right at the beginning! (Participant 1, community)

Monitoring family members was also a topic of concern for FCGs of PLWD who were hospitalized during the pandemic, where visiting restrictions prevented FCGs from being physically present. This was particularly problematic in circumstances where hospital staff did not have dementia-specific training. One FCG, for example, described her experience trying to advise unit staff on modifications to improve safety for her mother and other patients:

Because it was COVID and nobody could go in and see the situation, it was worse because I [didn't] even know what we were talking about in terms of the physical space . . . and [the nurse] made some comment around like "well if you have any other suggestions about what we could do in this space. . ." I'm like how am I going to have a suggestion when I haven't been there and I don't know what the unit looks like? If I hadn't advocated for [my mother to be moved], they would have just done a "wait and see" approach. . . just kept going and crossed their fingers. (Participant 19, distance and long-term care)

These examples highlight the importance of facilitating FCGs' ability to monitor the PLWD across the caregiving continuum, thus promoting the well-being of the PLWD, reducing stress for the FCG, and improving the ability of staff in hospitals or continuing care settings to provide safe and effective care.

Providing stimulation. Especially among FCGs in the community, participants reported difficulty being able to provide adequate social engagement and stimulation for the PLWD amid their other obligations and without the resources available prior to the pandemic:

I feel bad that I'm not offering enough stimulus for my wife, like all of her friends are back to [work] and. . . and so I feel like I should be, I would like to do more with her but I also have to work, so it's a big challenge. (Participant 8, community)

Community-based FCGs also emphasized that as their own mental health was impacted by the pandemic, it became increasingly difficult to provide enrichment and engagement for the PLWD:

Emotionally I'm struggling myself, so I'm not able to really give [my mother] the emotional connections that I would like to be able to give her. If I was [just] coming to visit her I could engage with her and talk [about] great things, but I can't do it now. (Participant 5, community)

A common thread among FCGs in the community was that being "all things" to the PLWD during the pandemic created a negative feedback loop where caregiving capacity steadily diminished, along with the quality of the care they

were able to provide, as well as the mental and physical health outcomes for the FCG and sometimes the PLWD:

With being everything and everybody, and being second brain, I don't have the time to sit down and be the care assistant as well. . . and with trying to manage everything else I couldn't be that full time or part time person, and then I was beginning to feel guilt because what do I drop, what do I leave out in order to offer that stimulation and if you offer that stimulation is it really acceptable? (Participant 4, community)

As this FCG emphasized, the increased cognitive load of both compensating for missing support resources and being the "second brain" for both herself and her spouse, was beginning to lead to burnout and guilt. These feelings were exacerbated by the additional responsibilities many FCGs had to juggle when trying to maintain their households during the pandemic.

Maintaining household(s). In addition to ensuring that the PLWD was receiving adequate care, FCGs also noted that the responsibilities of maintaining sometimes multiple households were made more challenging and burdensome during the pandemic. Most FCGs were responsible for daily errands (e.g., shopping, cleaning, and providing meals); arranging transportation for the PLWD (especially as supportive transportation services, taxis, and public transportation were cut back or no longer seen as safe), and making most major household decisions. As the resources that FCGs relied on were suddenly cut at the onset of the pandemic, many FCGs described a kind of "whiplash" in trying to cope. This was particularly burdensome for aging FCGs who were suddenly responsible for physically demanding work:

[Before] COVID hit I had help every day . . . we had the day programs twice a week, I had hired a driver, I had a couple of days of respite, I also had a housekeeper to do the hard stuff, I've had that for a few years because I'm getting older too. And of course all that disappeared, so I was totally on my own . . . I was doing a lot of yard work and I'm pretty much doing that all myself at this point, doing housework and big jobs I haven't had to do for probably about eight or so years. . . (Participant 6, community)

Many FCGs were also providing care for other family members in addition to the PLWD, whether they be children, aging parents, siblings, or other friends or relatives. FCGs expressed that, in the midst of the pandemic, managing all of these roles became increasingly challenging—often at the expense of the quality of care they were able to provide to the PLWD, as seen in the "providing stimulation" subtheme above.

Outcomes. The pandemic had a significant impact on the physical and mental health of both FCGs and PLWD. The third major theme, *outcomes*, describes these impacts, and was divided between the outcomes for FCGs and PLWD.

FCGs' comments about their own outcomes were split into subthemes of physical and mental health.

FCG physical health. FCGs dealt with a double-edged sword regarding their physical health, where COVID-19-related restrictions both limited the resources they had relied on to compensate for their own health issues and caused further health issues because of stress and overexertion:

I'm dealing with a lot of stress with my father and then mom, and I developed hypertension. . . at one point I ended up in emergency, and then a couple of weeks later my blood pressure went through the roof and so now I'm on blood pressure medication, [which] had bad side-effects. . . and in all of this I'm helping to take care of my mom so it's hard on me. (Participant 2, community)

This was particularly pronounced among those caregiving within the community, who had previously relied on external help to manage caregiving and household maintenance tasks, such as care aides, house cleaners, landscapers, and contractors.

It was kind of quiet at first, and rather pleasant because I didn't have all these people coming back and forth, but what happened was that I developed very, very disabling back pains, and so I went on heavy medication and I had physio treatments, [but] it wasn't helping. (Participant 6, community)

Many spousal FCGs are also older adults and were thus also managing health issues and complications due to their own aging process. They highlighted the added difficulty that their declining health, energy, and capabilities were causing them:

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. (Participant 7, community)

FCG mental health. FCGs indicated that their mental health had suffered during the pandemic, largely driven by social isolation, reduced resources, and increased uncertainty and fear for the future. This contributed to greater strain and burnout among FCGs.

Among FCGs in the community, increased strain and burnout were rooted in the necessity to "[be] everything and everybody" in the absence of external caregiving supports. In addition, for many community FCGs, burnout subsequently led to guilt for not being able to do it all. As described above, many FCGs reported feeling unable to offer adequate social stimulation and engagement for the PLWD in the wake of managing all their other duties, which in turn caused feelings of guilt and shame. Conversely, for FCGs of PLWD in continuing care, not being able to provide hands-on care, social stimulation, and emotional support to the PLWD had also caused feelings of guilt:

And because my mother knew her destiny [with dementia], you know I promised her “you will never be alone mom, you’ll never be alone, we’ll be there with you to the end.” So there’s also this feeling of broken promises, because you weren’t allowed to fulfill your promise to them. (Participant 16, long-term care)

Especially for FCGs whose family members were in later stages of dementia or declining rapidly, the mental health consequences of not being able to be present for their family member have been severe:

[When] I realized that she was probably not going to make it to the end of COVID. . . the first couple of months I was just hysterical and crying all the time. . . just that understanding that the care she was receiving, not that it was bad care, but it wasn’t enough and it just wasn’t going to be enough, and that she would not make it. (Participant 16, long-term care)

Reflecting on the families who were not able to secure visits with their family member, another caregiver emphasized the long-term toll of pandemic restrictions: “you’re going to be sweeping up scarred people for decades because of that situation” (Participant 20, long-term care).

FCGs also noted that their social isolation was having a negative impact on their well-being during the pandemic. With support groups and social gatherings suspended, few FCGs felt that they had the social network and support they needed to cope with both caregiving and the pandemic. As one FCG told us, “I think what I find the hardest is connecting up with people that are in a similar situation, that just instinctively know what you’re saying. . . it’s just the empathy, you know” (Participant 9, community). Ultimately, FCGs across the care continuum agreed that the mental health burden of caregiving during a pandemic has been, and will continue to be, severe:

The fallout of mental health in the midst of this pandemic, it’s a very real thing that we’re dealing with here right now, and it just compounds everything. (Participant 8, community)

PLWD outcomes. FCGs reported that reduced opportunities for physical activity and engagement, and increased social isolation, had negative impacts on the physical and mental health of PLWD across the care continuum. Community-based FCGs pointed to the consequences of social isolation on the PLWD and accelerated dementia progression as an unintended consequence of the public health restrictions. FCGs of PLWD in continuing care also saw dramatic declines in functional ability for their family member living with dementia:

You know because when . . . COVID started she was in pretty good shape, you know feeding herself, walking around with me, everything else and then she went downhill so quickly without

the input and stimulation that she needed. (Participant 16, long-term care)

FCGs also expressed mixed feelings of gratitude to the strict lockdown procedures at some continuing care facilities that not only prevented outbreaks, but also created additional stressors and reduced stimulation and/or care for the PLWD:

I think with dementia patients in particular the impact is quite [difficult], we know that social interaction and stimulus is a contributing factor to progression, and so I think it’s hard. . . I mean I’m really hard pressed to see how her decline isn’t somewhat correlated to those restrictions that ended up being in place. And so [while], 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. (Participant 19, long-term care)

FCGs of PLWD in continuing care also noted that, because of the intensified demands on staff and staffing shortages brought about by the pandemic, facility staff had a lower capacity to deal with responsive behaviors from their residents. This led to an increased reliance on short-term management strategies such as medication:

[When] COVID happened . . . 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. (Participant 12, long-term care)

FCGs also reported the challenges of having to move the PLWD between facilities during the pandemic as the PLWD’s current facility became unable to manage their responsive behaviors:

And then we were contacted to say that the supportive living that she was in could no longer handle her and her behaviours, so we had to move her in the middle of COVID which was frightening [as her] dementia is. . . fairly advanced . . . so she had no idea what was happening, they had to move her, then we had to isolate her, [and] she’s very mobile, so trying to isolate her for 14 days at the new location was very difficult, they had a lot of challenges there. (Participant 12, long-term care)

Overall, participants emphasized the strong negative impact of pandemic-related public health restrictions on the PLWD, an increase in responsive behaviors and severity of cognitive impairment, and how these changes intensified feelings of stress and guilt for the FCGs.

Recommendations from caregivers. The following recommendations were made by FCGs during the focus groups in response to the question “What could have been done to better support you and your PLWD during this health crisis?”

Table 2. Recommendations.

Recommendations	Description
1. Information use and needs	
(a) Accessible information	Present information in multiple formats in simple language
(b) Specific information	Information must be relevant to individual FCGs and granular enough for daily use and decision-making
(c) Centralized information	Use of a centralized information hub reduces burden and increases accessibility
2. Caregiving role	
(a) Dyadic, holistic approach	Tailored resources must address FCG and PLWD as a dyadic, interdependent unit
(b) Adaptive resources	Adapting resources to public health restrictions over shuttering them entirely
3. Outcomes	
(a) Social support for caregivers	Connecting FCGs with others in similar situations to combat social isolation
(b) Socialization and physical exercise for PLWD	Social engagement and physical activity must continue to be available to PLWD in the community and continuing care throughout the pandemic

Note. FCG = family caregiver; PLWD = people living with dementia.

Recommendations made by the FCGs were grouped under the three overarching themes: (a) Information use and needs, (b) Caregiving role, and (c) Outcomes (Table 2).

Information use and needs. FCGs emphasized that public health information must be provided in accessible formats, be centralized and easy to find, and be specific and relevant to their needs.

Accessible information. FCGs noted that they are a diverse group, and thus any resources intended to support them must be presented using multiple approaches and mediums. This helps to ensure that each FCG has access to a format that is applicable to them and meets their needs, for instance, using a variety of digital, televised, radio, and print media to convey information. In addition to using many different formats and distribution strategies, language must be simple, clear, and accessible.

Specific information. Amid the overload of information about COVID-19, public health restrictions, and facility visitation guidelines, FCGs noted that there was very little information for them specifically about how the pandemic was affecting their role as caregivers or how to cope among the uncertainty. The three areas where FCGs could have used more information were as follows: localized information about incidence and prevalence to help in making risk assessments and decisions about everyday activities, information about changes to caregiving during the pandemic, and information about how decisions about restrictions would be made in the future.

FCGs noted that their anxiety could have been lessened with access to tailored information addressing their *specific* challenges and questions during the pandemic. Questions about how to explain the pandemic to a PLWD; how to encourage mask wearing, hand washing, and physical distancing; or how services were changing with restrictions and how to cope would have been useful and reassuring for

FCGs. Information about how other FCGs were coping with the changes would have helped fill an information gap and reduced feelings of isolation.

Centralized information. FCGs expressed feelings of being overwhelmed trying to navigate a changing system during the pandemic, learn which supports were still being offered, and how to access them. A centralized hub for information about supports and referrals could have addressed this challenge.

Caregiving role. To support FCGs in their care provision, resources must be tailored to their unique needs and address the FCG and PLWD as a unit, and use creative adaptations to continue serving FCGs during public health emergencies.

Dyadic/holistic approach to support. FCGs stressed that effective interventions must consider the PLWD and the caregiver simultaneously, within their caregiving context. Siloed solutions often failed to understand the PLWD and caregiver as a dyad, whose needs intersect with one another and their environment, which for our participants meant that their needs went unmet and/or the FCG spent large amounts of time and effort trying to bridge the gaps. This was true for dyads across the care continuum: FCGs are essential care partners in continuing care settings—not simply “visitors”—just as they are in the community. In public health emergencies, successful interventions must support the FCG and PLWD as a unit, and recognize the challenges experienced by both caregiver and the person for whom they provide care.

Adaptive resources. FCGs in the community emphasized the burden that shuttering respite, home care, and day programs put on them, and expressed a deep need for creative adaptations that would allow these services to continue operating safely during a health emergency. Whereas some FCGs had success with day programs that pivoted to a virtual environment, many others had not seen the same engagement

from the PLWD and required in-person solutions. FCGs suggested nontraditional formats for outdoor home care visits and extra precautions that would allow respite care to continue.

Outcomes. Social isolation and lack of physical activity had negative impacts on the physical and mental health outcomes of FCGs and PLWD. To alleviate that impact, opportunities for social, physical, and emotional support must be maintained for both members of the dyad, regardless of where they fall along the care continuum.

FCG support groups and connection. Social isolation was a key factor impacting FCG mental health and caregiving capacity during the pandemic. In the focus groups, FCGs expressed the desire to have continued connection with other FCGs in similar situations as themselves during the pandemic. Community-based FCGs noted that, during the pandemic, virtual or telephone-based support groups were sometimes of limited utility because the PLWD became suspicious of what was being discussed. As with all other resources, support groups should be fostered across diverse models, including text-based message boards or email groups, virtual video or telephone calls, and physically distanced and/or outdoor meetups when safe.

PLWD socialization and physical exercise. FCGs were adamant that, regardless of public health restrictions, PLWD residing in continuing care *must* have access to ongoing social engagement and physical activity. They stressed that, while this may require creative thinking and proactive planning, social isolation for PLWD should not be an acceptable option.

Many PLWD were not able to recognize and connect with family members through virtual conference calls or window visits. The nature of dementia, and the degree of its progression, can make video conferencing and digital communication formats extremely challenging or impossible to effectively utilize. Building capacity within facilities to support physical and social activity during lockdown should be a priority going forward.

Discussion

During the COVID-19 pandemic, FCGs faced increased challenges with decreased support in many of the roles they have been required to fill. As caregivers, household managers, social and emotional supports, and advocates for the PLWD, FCGs were left unsupported and socially isolated. They also lacked accessible, centralized, and specific information relevant to their individual situations. The impact of the pandemic and related COVID-19 public health restrictions were, and continue to be, far-reaching, touching all facets of the caregiving role and the mental and physical health outcomes for both the FCG and the PLWD. Alleviating those impacts requires shifting the way we think about providing information, resources, and supports under emergency conditions.

There are no simple solutions to the COVID-19 pandemic, or how to adequately support FCGs and PLWD while also protecting them from infection. However, it is clear that, as health care has increasingly transitioned out of formal settings and into the community (Kent et al., 2020), the system's reliance on FCGs is unequivocal (Romanow, 2002). This is true across the care continuum as FCGs also provide critical support for PLWD in continuing care (Hindmarch et al., 2021; Wammes et al., 2020). At the onset of the COVID-19 pandemic, however, the essential role of FCGs seemed to be undervalued as they were restricted from continuing care facilities and crucial community resources were shuttered (Irani et al., 2021; Stall et al., 2020; Tsapanou et al., 2021). Creative solutions to achieving *both* ends—preventing infection while maintaining FCG support and access to the PLWD—should instead be the goal (Meisner et al., 2020).

FCGs themselves should always be a primary source of information when considering the best ways to creatively adapt information, resources, and supports under emergency conditions. The recommendations made by the FCGs in this study represent a solid foundation from which to reimagine communication and intervention both during the ongoing COVID-19 pandemic and in future public health emergencies. FCGs reported feelings of not only being overwhelmed by the volume of information available, but also frustrated by the paucity of information relevant to their specific circumstances. We therefore echo their calls for information that is simple, specific, and centralized, which would reduce feelings of stress and anxiety and potentially improve dyad outcomes and resource uptake.

We also align with FCGs' calls for resources that are tailored and consider the dyads' specific circumstances as a whole. An essential component of a dyadic approach would include regular caregiver assessments, which would help pivot the focus from reactive care to proactive support of the caregiving dyad and tailor supports and resources to address their diverse caregiving situations. Through regular assessments and check-ins, health and social support services could address issues in a timely and applicable manner to improve outcomes for the caregiving dyad.

Adaptive resources that find creative ways to continue providing support to dyads are also crucial for improving outcomes for both the FCG and PLWD (Nash et al., 2021). Adequate provisions and accommodations that allow continued social contact and stimulation for PLWD residing in continuing care is essential (Phinney, 2006) and, similarly, FCGs require continued mental health and social support across a variety of platforms. This includes support groups and connection with other FCGs, individualized mental health support, and accommodations that facilitate their taking care of their own medical issues, such as allowing the PLWD to accompany them to appointments, facilitating respite, and relevant referrals based on assessments as described above.

A key challenge identified by FCGs was the fragmentation of the health and social support systems, leading to feelings of

confusion and having “fallen through the cracks.” As with so many aspects of the experiences described by FCGs, this is an ongoing challenge for health and social care systems as the chronic fragmentation of support services has only been exacerbated by the pandemic (Lyons & Lee, 2018). Dramatic changes in resourcing, communication within the systems, and effective use of caseworkers or health care navigators could potentially alleviate some of the issues experienced by FCGs (McGhan et al., 2022). These changes are important as the issues described by FCGs predate the pandemic, have characterized each wave of the pandemic, and will continue to cause harm beyond its conclusion. Given the growing certainty of ongoing disruptive society, and planetary-level health events, creating robust systems that continue to protect our most vulnerable populations is of the utmost importance (International Family Nursing Association, 2020).

Limitations

Focus groups are by necessity limited in size, and thus our results are not necessarily representative nor transferable. Our sample, while distributed across the caregiving continuum, was demographically quite homogeneous, with all participants being well-educated White women. Greater work needs to be done to reach a more diverse body of caregivers, including racialized people, socially and economically marginalized caregivers, male caregivers, and rural caregivers, to ensure that their experiences and needs are also represented in research and policy decisions. These focus groups also represent a single point in time between the first and second waves of the pandemic and do not shed light on the additional concerns and needs that have developed and changed as the pandemic stretched into its second and now third year.

Conclusion

We have made recommendations based on the comments of the FCGs in our study about how to better support FCGs during the ongoing COVID-19 pandemic, the revolving public health restrictions, and in future public health emergencies. Information needs to be accessible, centralized, and specific; support programs need to be holistically focused on both members of the caregiving dyad. In addition, resources must be adaptive to changing levels of restrictions, restrictions must make adequate provisions for FCGs to receive the resources and social supports they need to continue caregiving, and provisions to guard against social isolation and maintain physical activity must be addressed to be beneficial for both members of the caregiving dyad.

Considering the essential role of FCGs when evaluating public health actions is vital for protecting the well-being of FCGs, PLWD, and the overall functioning of the health care system. The voices of FCGs should be a primary source of information and insight, both in the context of a public health

emergency and during “normal” times. Although the impacts of the pandemic and related COVID-19 public health restrictions have had unintended consequences, they present an opportunity to reframe the way we consider of the role of FCGs for PLWD, and the best ways of providing information, resources, and support under emergency conditions.

Acknowledgments

The authors would like to acknowledge the support of Whitney Hindmarch in the collection and analysis of the data used in this study. Special thank you to the Alzheimer Society of Calgary for their generous financial support of this study. Also, thank you to the Alzheimer Society of Calgary and Dementia Network Calgary for their instrumental guidance through all stages of the research study design and implementation. Thank you to the members of the Community Advisory Committee whose insight and knowledge were instrumental in guiding the study. Finally, thank you to all of the family caregivers who participated in the study and shared their time and expertise.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Funding for this study was generously provided by the Alzheimer Society of Calgary.

ORCID iD

Kristin Flemons  <https://orcid.org/0000-0001-7911-2854>

Note

1. We define family caregiver (FCG) as an unpaid individual (e.g., a spouse, partner, family member, friend, or neighbor) involved in assisting the people living with dementia (PLWD) with activities of daily living and/or everyday tasks.

References

- Arriagada, P. (2020). *Insights on Canadian Society: The experiences and needs of older caregivers in Canada*. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00007-eng.htm>
- Boscart, V. M., McNeill, S., & Grinspun, D. (2019). Dementia care in Canada: Nursing recommendations. *Canadian Journal on Aging/La Revue Canadienne du Vieillessement*, 38(3), 407–418. <https://doi.org/10.1017/S071498081800065X>
- 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. (2016). *Unpaid caregiver challenges and supports*. <https://www.cihi.ca/en/dementia-in-canada/unpaid-caregiver-challenges-and-supports>
- Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers*

- in *Neurology*, 3, Article 73. <https://doi.org/10.3389/fneur.2012.00073>
- Chambers, L. W., Bancej, C., & McDowell, I. (2016). *Prevalence and monetary costs of dementia in Canada*. Alzheimer Society of Canada.
- Duncan, K. A., Shooshtari, S., Roger, K., Fast, J., & Han, J. (2020). The cost of caring: Out-of-pocket expenditures and financial hardship among Canadian carers. *International Journal of Care and Caring*, 4(2), 141–166. <https://doi.org/10.1332/239788220X15845551975572>
- Family Caregiver Alliance. (2019). *Caregiver statistics: Demographics*. <https://www.caregiver.org/resource/caregiver-statistics-demographics/>
- Giebel, C., Lord, K., Cooper, C., Shenton, J., Cannon, J., Pulford, D., Shaw, L., Gaughan, A., Tetlow, H., Butchard, S., Limbert, S., Callaghan, S., Whittington, R., Rogers, C., Komuravelli, A., Rajagopal, M., Eley, R., Watkins, C., Downs, M., . . . Gabbay, M. (2021). A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *International Journal of Geriatric Psychiatry*, 36(3), 393–402. <https://doi.org/10.1002/gps.5434>
- Greenberg, N. E., Wallick, A., & Brown, L. M. (2020). Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *Psychological Trauma: Theory, Research, Practice, and Policy*, 12(Suppl. 1), S220–S221. <https://doi.org/10.1037/tra0000793>
- Harris, M. (2017). Recognizing the important role of family caregivers. *Home Healthcare Now*, 35(10), 579–579. <https://doi.org/10.1097/NHH.0000000000000623>
- Hindmarch, W., McGhan, G., Flemons, K., & McCaughey, D. (2021). COVID-19 and long-term care: The essential role of family caregivers. *Canadian Geriatrics Journal*, 24(3), 195–199. <https://doi.org/10.5770/cgj.24.508>
- Hoffman, G. J., Webster, N. J., & Bynum, J. P. W. (2020). A framework for aging-friendly services and supports in the age of COVID-19. *Journal of Aging & Social Policy*, 32(4–5), 450–459. <https://doi.org/10.1080/08959420.2020.1771239>
- Hollander, M. J., Liu, G., & Chappell, N. L. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 42–49. <https://doi.org/10.12927/hcq.2009.20660>
- Honea, N. J., Brintnall, R., Given, B., Sherwood, P., Colao, D. B., Somers, S. C., & Northouse, L. L. (2008). Putting evidence into practice: Nursing assessment and interventions to reduce family caregiver strain and burden. *Clinical Journal of Oncology Nursing*, 12(3), 507–516. <https://doi.org/10.1188/08.CJON.507-516>
- Institute for Health Metrics and Evaluation. (2019). *Global burden of disease study 2019 (GBD 2019) data resources*. GHDx. <http://ghdx.healthdata.org/gbd-2019>
- International Family Nursing Association. (2020). *IFNA position statement on planetary health and family health*. <https://internationalfamilynursing.org/2020/04/18/ifna-position-statement-on-planetary-health-and-family-health/>
- Irani, E., Niyomyart, A., & Hickman, R. L. (2021). Family caregivers' experiences and changes in caregiving tasks during the COVID-19 pandemic. *Clinical Nursing Research*, 30(7), 1088–1097. <https://doi.org/10.1177/10547738211014211>
- Keefe, J. (2020, May 12). COVID-19 is demonstrating the value of family caregivers. *Policy Options*. <https://policyoptions.irpp.org/magazines/may-2020/covid-19-is-demonstrating-the-value-of-family-caregivers/>
- Kent, E. E., Ornstein, K. A., & Dionne-Odom, J. N. (2020). The family caregiving crisis meets an actual pandemic. *Journal of Pain and Symptom Management*, 60(1), e66–e69. <https://doi.org/10.1016/j.jpainsymman.2020.04.006>
- Kolanowski, A., Boltz, M., Galik, E., Gitlin, L. N., Kales, H. C., Resnick, B., Van Haitsma, K. S., Knehans, A., Sutterlin, J. E., Sefcik, J. S., Liu, W., Petrovsky, D. V., Massimo, L., Gilmore-Bykovskiy, A., MacAndrew, M., Brewster, G., Nalls, V., Jao, Y.-L., Duffort, N., & Scerpella, D. (2017). Determinants of behavioral and psychological symptoms of dementia: A scoping review of the evidence. *Nursing Outlook*, 65(5), 515–529. <https://doi.org/10.1016/j.outlook.2017.06.006>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.
- Lyons, K. S., & Lee, C. S. (2018). The theory of dyadic illness management. *Journal of Family Nursing*, 24(1), 8–28. <https://doi.org/10.1177/1074840717745669>
- McGhan, G., McCaughey, D., Flemons, K., Shapkin, K., Parmar, J., Anderson, S., & Poole, L. (2022). Tailored, community-based programs for people living with dementia and their family caregiver. *The Journal of Gerontological Nursing*, 48(4), 26–32. <https://doi.org/10.3928/00989134-20220401-06>
- Meisner, B. A., Boscart, V., Gaudreau, P., Stolee, P., Ebert, P., Heyer, M., Kadowaki, L., Kelly, C., Levasseur, M., Massie, A. S., Menec, V., Middleton, L., Taucar, L. S., Thornton, W. L., Tong, C., van den Hoonaard, D. K., & Wilson, K. (2020). Interdisciplinary and collaborative approaches needed to determine impact of COVID-19 on older adults and aging: CAG/ACG and CJA/RCV Joint Statement. *Canadian Journal on Aging/La Revue Canadienne du Vieillessement*, 39(3), 333–343. <https://doi.org/10.1017/S0714980820000203>
- Nash, W. A., Harris, L. M., Heller, K. E., & Mitchell, B. D. (2021). “We are saving their bodies and destroying their souls.” Family caregivers' experiences of formal care setting visitation restrictions during the COVID-19 pandemic. *Journal of Aging & Social Policy*, 33(4–5), 398–413. <https://doi.org/10.1080/08959420.2021.1962164>
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1–13. <https://doi.org/10.1177/1609406917733847>
- O'Rourke, N., Cappeliez, P., & Guindon, S. (2003). Depressive symptoms and physical health of caregivers of persons with cognitive impairment: Analysis of reciprocal effects over time. *Journal of Aging and Health*, 15(4), 688–712. <https://doi.org/10.1177/0898264303256514>
- Phinney, A. (2006). Family strategies for supporting involvement in meaningful activity by persons with dementia. *Journal of Family Nursing*, 12(1), 80–101. <https://doi.org/10.1177/1074840705285382>
- Romanow, R. (2002). *Building on values: The future of health care in Canada*. Commission on the Future of Health Care in Canada. <http://publications.gc.ca/site/eng/9.648673/publication.html>
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American Journal of*

- Nursing*, 108(Suppl. 9), 23–27. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>
- Sinha, M. (2013). *Spotlight on Canadians: Results from the general social survey: Portrait of caregivers, 2012*. Statistics Canada. <http://www.deslibris.ca/ID/240440>
- Stall, N. M., Johnstone, J., McGeer, A. J., Dhuper, M., Dunning, J., & Sinha, S. K. (2020). 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. *Journal of the American Medical Directors Association*, 21(10), 1365–1370. e7. <https://doi.org/10.1016/j.jamda.2020.07.038>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Tsapanou, A., Papatriantafyllou, J. D., Yiannopoulou, K., Sali, D., Kalligerou, F., Ntanasi, E., Zoi, P., Margioti, E., Kamtsadeli, V., Hatzopoulou, M., Koustimpi, M., Zagka, A., Papageorgiou, S. G., & Sakka, P. (2021). The impact of COVID-19 pandemic on people with mild cognitive impairment/dementia and on their caregivers. *International Journal of Geriatric Psychiatry*, 36(4), 583–587. <https://doi.org/10.1002/gps.5457>
- Wammes, J. D., Kolk, D., van den Besselaar, J. H., MacNeil-Vroomen, J. L., Buurman-van Es, B. M., & van Rijn, M. (2020). Evaluating perspectives of relatives of nursing home residents on the nursing home visiting restrictions during the COVID-19 crisis: A Dutch cross-sectional survey study. *Journal of the American Medical Directors Association*, 21(12), 1746–1750. e3. <https://doi.org/10.1016/j.jamda.2020.09.031>
- World Health Organization. (2020). *Dementia fact sheets*. <https://www.who.int/news-room/fact-sheets/detail/dementia>
- publications include “Tailored, Community-Based Programs for People Living With Dementia and Their Family Caregiver” in *Journal of Gerontological Nursing* (2022, with G. McGhan et al.), “COVID-19 and Long-Term Care: The Essential Role of Family Caregivers” in *Canadian Geriatrics Journal* (2021, with W. Hindmarch, G. McGhan, & D. McCaughey), and “Barriers to Implementing Internist Recommendations for Perioperative Anticoagulation Management by Surgical Teams: A Qualitative Study” in *Canadian Journal of General Internal Medicine* (2022, with M. Bosch et al.).
- Gwen McGhan**, RN, PhD, GNC(c) is an assistant professor in the Faculty of Nursing at the University of Calgary, Canada. Her research interests include using a person and family-centered care lens to develop tailored interventions that target the needs of older adults living with dementia and their care partners. Her current research focus is on understanding how the COVID-19 pandemic and associated public health measures are influencing care provision and wellness for persons living with dementia and their family caregivers across the care continuum. Her recent publications include “Tailored, Community-Based Programs for People Living With Dementia and Their Family Caregiver” in *Journal of Gerontological Nursing* (2022, with D. McCaughey et al.) and “COVID-19 and Long-Term Care: The Essential Role of Family Caregivers” in *Canadian Geriatrics Journal* (2021, with W. Hindmarch, K. Flemons, & D. McCaughey).
- Deirdre McCaughey**, PhD, MBA, is an associate professor in the Cumming School of Medicine, Department of Community Health Sciences at the University of Calgary. The overarching theme of her research investigates structural factors (e.g., systems and processes, leadership, and organizational culture) in health care institutions and systems that influence patient/family access and outcomes, organizational effectiveness, and health care provider/workforce wellness. Her recent publications include “Tailored, Community-Based Programs for People Living With Dementia and Their Family Caregiver” in *Journal of Gerontological Nursing* (2022, with G. McGhan et al.) and “COVID-19 and Long-Term Care: The Essential Role of Family Caregivers” in *Canadian Geriatrics Journal* (2021, with W. Hindmarch, G. McGhan, & K. Flemons).

Author Biographies

Kristin Flemons, MA, is a research associate with the W21C Research and Innovation Center at the University of Calgary, Canada. She is trained as a medical anthropologist and her research interests include social determinants of health, health equity, access to care, and epistemic shifts in health and medicine. Her recent