



Exploring the Impacts of COVID-19 Public Health Measures on Community-Dwelling People Living With Dementia and Their Family Caregivers: A Longitudinal, Qualitative Study

Jennifer Baumbusch, RN, PhD¹ , Heather A. Cooke, PhD¹ ,
Kishore Seetharaman, MS, BArch², Aneesa Khan¹,
and Koushambhi Basu Khan, PhD¹

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Abstract

Since the onset of the COVID-19 pandemic, community-dwelling people living with dementia and their family caregivers have experienced many challenges. The unanticipated consequences of public health measures have impacted these families in a myriad of ways. In this interpretive policy analysis, which used a longitudinal, qualitative methodology, we purposively recruited 12 families in British Columbia, Canada, to explore the impacts of pandemic public health measures over time. Semi-structured interviews were conducted every 3 months and participants completed diary entries. Twenty-eight interviews and 34 diary entries were thematically analyzed. The findings explore ways that families adopted and adapted to public health measures, loss of supports, both formal and informal, and the subsequent consequences for their mental and physical well-being. Within the ongoing context of the pandemic, as well as potential future wide-spread emergencies, it is imperative that programs and supports are restarted and maintained to avoid further harm to these families.

Keywords

COVID-19, dementia, family caregivers, qualitative

In 2020, the SARS-CoV-2 virus (hereafter referred to as COVID-19) spread globally leading to a worldwide pandemic (World Health Organization, 2020). Jurisdictions introduced broad public health measures to try to stop or slow the spread of the virus. These public health measures have had unintended consequences particularly for populations that were already experiencing structural vulnerabilities related to age, race, gender, disability, and class (Blundell et al., 2020). People living with dementia and their family caregivers are among the populations that have been disproportionately impacted by the pandemic and associated public health measures.

Community-dwelling people living with dementia across the world experienced severe consequences of the pandemic and of COVID-19 mitigating measures adopted to limit the spread in the community. In the United Kingdom, the public health measures adopted ranged from nationwide lockdowns to local tier-based restrictions with a guiding policy of “shielding” those at risk, such as older adults over 70 years of age (Sriram et al., 2021). Accordingly, closures of day

programs, among other support services, which provide socialization for people living with dementia and respite for caregivers, occurred early in the pandemic as a part of this “shielding policy.” A study with 569 participants (people living with dementia, family caregivers, and older people) in the United Kingdom indicated that such closures contributed to worse quality of life and increased anxiety among those affected by dementia (Giebel, Cannon, et al., 2021). Qualitative research with people living with dementia also reflected concerns about social isolation, anxiety, and loss of confidence in their ability to participate in society (Talbot & Briggs, 2021).

¹The University of British Columbia, Vancouver, Canada

²Simon Fraser University, Burnaby, British Columbia, Canada

Corresponding Author:

Jennifer Baumbusch, Associate Professor, School of Nursing, The University of British Columbia, T201-2111 Westbrook Mall, Vancouver, British Columbia, Canada V6T 2B5.
Email: Jennifer.baumbusch@ubc.ca

While countries like Hong Kong adopted strict quarantine and social distancing measures working toward a zero COVID-19 goal, the focus nevertheless was on the most vulnerable leading to the closures of geriatric day hospital services and other community services for older people, including the day care centers (Yeung et al., 2020). Loss of such programs led to physical changes, as was noted in a study with caregivers in Hong Kong, where the majority of participants shared that their relative had experienced deterioration in mobility and cognitive function during closures (Wong et al., 2022). Other country-specific studies, with similar restrictive public health measures, also suggest the deterioration of motor capacities, physical and mental health, and general well-being among community-dwelling people living with dementia following the closure of social support services and programs and other public health restrictions that limit social interaction and participation (Barguilla et al., 2020; Giebel, Cannon, et al., 2021; Roach et al., 2021; Talbot & Briggs, 2021). In a Dutch study with 389 participants ($N = 121$ with dementia; $N = 268$ without dementia), the COVID-19 pandemic was associated with an increase in behavioral symptoms, for example, apathy and aggression, as well as psychological symptoms, for example, feelings of anxiety, depression, and uncertainty (van Maurik et al., 2020).

Family caregivers of people living with dementia in the community also experienced the impacts of public health measures. In addition to the closure of day programs, many in-home formal supports also decreased or stopped during the pandemic. In a Norwegian study, in-home care responsibilities (e.g., personal hygiene, supervision) shifted to family caregivers, increasing their weekly care work by 100% (Vislapuu et al., 2021). In a recent study examining the differences in health during the pandemic between non-caregivers and short-term caregivers and long-term caregivers, both short-term and long-term caregivers experienced poorer mental health and greater fatigue than non-caregivers, and long-term caregivers were found to be more likely to report somatic symptoms (e.g., headaches, body aches, and abdominal discomfort) (Park, 2021). It has been suggested that the amplified caregiving challenges during COVID-19 are linked to loneliness, social isolation, and increased stress and physical, emotional, and mental health needs among informal/family caregivers (Barguilla et al., 2020; Greenberg et al., 2020; Roach et al., 2021). Research also suggests that family caregivers of people living with severe dementia experience greater stress during the pandemic than caregivers of people with mild to moderate dementia (Cohen et al., 2020).

Prior to the onset of the pandemic, our team had developed a longitudinal qualitative study to explore the experiences of community-dwelling people living with dementia and their family caregivers, with particular emphasis on the use of health and social care services. Data collection for the study coincided with the start of the pandemic, and therefore our study aim pivoted to better understand the unanticipated consequences of pandemic public health measures on this

population. The longitudinal aspect of our research that allows for the use of varied data collection tools over time seemed particularly suited in this context to analyze how families experienced and adjusted to shifting pandemic measures over time. Thus, the research question became, "How have COVID-19 public health measures impacted community-dwelling people living with dementia and their family caregivers over time?"

Method

The theoretical and methodological underpinnings of this study were informed by longitudinal interpretive policy analysis. We sought to understand how people living with dementia and their caregivers were experiencing progression of the disease and support needs over time. With the onset of the pandemic, a number of policies in the form of public health orders were introduced in the study setting, which reshaped health and social care services for this population, and had consequences for individuals' mental and physical health. Interpretive policy analysis is an approach that aims to understand the consequences of policies for those who experience them (Yanow, 2000). Longitudinal qualitative research is the method of inquiry layered into this approach with a particular focus on the temporal aspects of the experience (Neale & Flowerdew, 2003). Furthermore, it allows for an in-depth examination of the texture of lived experiences of study participants through multiple data collection methods. Research ethics approval for the study was obtained from The University of British Columbia's Behavioural Research Ethics Board.

Setting

British Columbia (BC), Canada's westernmost province, was the setting for this study. The pandemic arrived in BC in late January 2020 when the first case of COVID-19 was identified. A public health emergency was declared in mid-March 2020, with a provincial state of emergency announced on March 18 (CBC News, 2020). During this time, public health measures were introduced that led to the closure of day programs for people living with dementia, as well as restrictions on social gatherings and other measures (BC Centre for Disease Control, 2020). As of January 2022, the province has had four waves of the pandemic and is currently being impacted by the Omicron variant. Throughout this entire time, people living with dementia had limited access (mainly virtual) to day programs and many formal in-home supports also decreased or were declined by families concerned about infection.

Recruitment and Participants

A purposive sample of 12 families was recruited starting in August 2020 using a variety of approaches. Advertisements

were posted on social media (e.g., Facebook, Twitter) and included in newsletters of non-profit organizations serving older adults and the provincial Alzheimer Society. Word of mouth was another avenue for recruitment. Recruitment materials highlighted how participation would help researchers better understand the experiences of care provision and health system navigation over time. Inclusion criteria were: being the primary caregiver for a community-dwelling individual living with dementia (ideally residing in the same household) in British Columbia, Canada, and fluency in English. Upon initial contact from caregivers, H.A.C. screened potential participants, asking caregivers to identify what percentage of the time they were solely responsible for their relative's care, and when their relative had received a diagnosis of dementia, and provided further information about the study. This conversation was followed by obtaining written informed consent from those caregivers who qualified and were interested in participating in the research.

Data Collection

Data were collected between August 2020 and August 2021 through semi-structured interviews and diaries. This period of time reflects Waves 2 and 3 of the pandemic in the study setting. In the pre-pandemic development of the study, we also planned to conduct in-home participant observations, which would include the person living with dementia in the data collection. However, due to public health measures, data collection needed to be conducted remotely and therefore we were restricted to interviews via an online platform or the telephone, and diary entries completed by caregivers.

Semi-structured interviews were conducted with each participant and were typically conducted via Zoom, with the exception of two participants who preferred to be interviewed by phone. During the year of data collection, up to three interviews were conducted with each participant for a total of 28 interviews (12 first interviews, 10 second interviews, and 6 third interviews). Initial interviews explored the family's dementia journey so far, including receipt of the initial diagnosis, daily routines and supports. Sociodemographic data were also collected at this time. At the second interview, conducted on average 3 months after the first, we explored informal supports and introduced more explicit questions about the impact of the pandemic on the family. The third interview, conducted on average 6 months after the first interview, continued to explore the family's well-being and also asked about COVID-19 vaccines, which had been introduced (see Table 1 for interview questions).

The interviews were all conducted by H.A.C. for consistency and to build rapport with the participants. Interviews ranged in length from 48 to 132 min (mean of 85 min for first interview, 66 min for second interview, and 69 min for third interview). All interviews were digitally recorded and transcribed verbatim; field jottings from the interviews were transcribed into more detailed field notes as soon as possible

following the interview. Participants were assigned a code to ensure anonymity and confidentiality and are identified by this code in the Findings section along with the date and type of data collection.

In addition to interviews, the diary method was employed with participants completing up to 6 months of diary entries from March to August 2021. The diary portion offered situated, in-depth data about participants' everyday lives not available via other methods (Herron et al., 2019). The monthly diary entries included both a structured (e.g., listing of interactions with health and social care services) and unstructured component (e.g., written narrative focused on the caregiver role and the highs and lows of the caregiving experience). In the unstructured part, to foreground their lived experiences, the participants were encouraged to reflect on their caregiving experience in that month and to include whatever stood out for them. Each month a research team member sent the diary request to participants and followed up once with a reminder. In total, we received 34 diary entries. Individual participants completed between two and six entries. Diary entries were primarily completed in a digital format, although several caregivers submitted paper copies, which were subsequently transcribed.

Data Analysis

Data management and analysis occurred concurrently with data collection, with NVivo 12 used to manage and organize all interview and diary transcripts, and interview field notes. Thematic analysis was used to identify patterns within and across the data with regard to participants' caregiving experiences and perspectives (Braun & Clarke, 2013) and occurred via several steps. Interviews and diary entries were read to obtain an understanding of each family's journey. K.B.K., a PhD-prepared researcher, then coded each piece of data (interview transcripts, field notes and diary entries), resulting in the development of a codebook complete with individual codes, descriptions, and exemplars. Biweekly data analysis meetings with the research team (three PhD-prepared researchers, one doctoral candidate) provided opportunities for collective analysis and further refinement of the codebook. Data were subsequently collated into meaningful groupings with similar, related codes further grouped into broader categories and themes. For instance, coding the longitudinal data set revealed the impact the pandemic was having on the different aspects of participants' lives. The team overtime through intense discussions refined multiple times the subcodes of the broader code of "Impact of COVID-19" to include the impact of disruptions in formal/informal as well as family supports, additional caregiving duties related to pandemic (buying supplies, following safety rules), and the overall mental health consequences on participants, among many other issues. Our findings in this article reflect on these recurring key themes in the data.

Table 1. Sample Interview Guide Questions.

Interview 1	<ol style="list-style-type: none"> 1. Tell me about your dementia journey as a caregiver so far. <ol style="list-style-type: none"> a. When did you first notice the person you care for might have cognitive changes? b. What happened during the journey to a diagnosis? How was the diagnosis introduced? Who shared it with you? c. What types of services and supports did you access early in the dementia journey? d. What types of services and supports did you access before COVID-19 precautions (e.g., in the Fall of 2019)? e. Do you think your gender or the gender of the person you care for influenced this journey in any ways? 2. In addition to the support you provide your relative, did they have any other in-home supports in the Fall of 2019? <ol style="list-style-type: none"> a. Did they receive home support services (e.g., a staff person comes to your home to help with various activities)? b. Are in-home supports paid for by the health authority (with a client co-payment) or do you pay out-of-pocket? If you pay out-of-pocket, approximately how much do you pay per month? c. Did they attend any community programs, such as an adult day program, or respite? d. Do other relatives also help with care? If so, how? e. Do other members of your community help with care (e.g., neighbors, friends, church members)? If so, how? f. How have formal in-home or community-based supports changed since COVID-19 precautions came into effect? 3. Could you describe the kind of day-to-day help and support you provide for the person you care at home at this point in time, particularly in relation to their dementia? 4. Is there anything else you'd like to tell me about your experiences as a caregiver for someone living with dementia?
Interview 2	<ol style="list-style-type: none"> 1. We like to say "family is who the person says it is." Can you tell me about who is in your family (can include pets; people who live in the same household or not)? 2. In addition to your "family," who else is part of your support network? <ol style="list-style-type: none"> a. Friends, neighbors, etc. 3. Has your family/support network changed since your relative's dementia diagnosis? 4. Were there people who were part of this network before and aren't any longer? Or vice versa, who you have connected with since the dementia diagnosis? 5. In terms of your support network (unpaid), has this changed since the onset of the pandemic? <ol style="list-style-type: none"> a. Who is in your "bubble?" How do they support you/your relative? 6. The pandemic restrictions really came into force last Spring in late February and into March. How have the restrictions impacted your formal supports? <ol style="list-style-type: none"> a. For example, did your relative attend an adult day program? How has this changed? b. If you are doing "virtual" supports, do you have access to the necessary technology (e.g., laptop/iPad, WiFi bandwidth)? c. Did you have in-home support before (e.g., paid companion or home support workers)? Has this changed? How? What factors led to the change (e.g., restricting people in your home to feel safer, lack of personal protective equipment)? d. Would you want in-home supports at this time if you could? Would you like out of home supports, such as an adult day program with appropriate infection control protocols?
Interview 3	<ol style="list-style-type: none"> 1. What percentage of the time would you say you're solely responsible for your relative's care? Has this changed from the last time we spoke? 2. Tell me about the impact of having had the COVID-19 vaccine on the services you're accessing or on your day-to-day life. 3. As we're now one year into the pandemic, what supports do you require going forwards?

Study Rigor

Trustworthiness was facilitated through creation of an audit trail of transcripts and minutes from research team meetings, which were held via Zoom (Onwuegbuzie & Leech, 2007) and the analysis of reflexive field notes. In addition, biweekly analysis sessions facilitated individual and joint analysis during which coding and categorization processes were discussed, clarified, and consensus achieved. Prolonged engagement with the data and the inclusion of verbatim data excerpts accompanied by researcher interpretation also contribute to trustworthiness.

Findings

Participant Characteristics

Twelve families participated with the primary caregiver (10 women, 2 men) as key informant during data collection. Participants' ages ranged from 36 to 82 years, with an average age of 61.8 years. In terms of relationship with the person living with dementia, five participants were spouses, five were daughters, one was a daughter-in-law, and one was a sibling. Nine of the participants were retired, one was employed full-time, one was employed part-time, and one

Table 2. Participant Demographics.

Descriptive characteristics	Total sample (N = 12)	%
Age (years)		
Mean	61.8	
Range	36–82	
Gender		
Female	10	83
Male	2	17
Education level		
High school diploma	3	25
College diploma	5	42
University degree	4	33
Race		
White	11	92
Biracial	1	8
Relation to person living with dementia		
Spouse	5	42
Daughter	5	42
Daughter-in-law	1	8
Sibling	1	8
Employment status		
Full-time	1	8
Part-time	1	8
Retired	9	75
Not employed	1	8
Annual income (household)		
<\$20,000	1	8
\$21,000–\$40,000	0	0
\$41,000–\$60,000	3	25
\$61,000–\$80,000	4	33
\$81,000–\$100,000	1	8
>\$101,000	2	17
Prefer not to say	1	8
Language primarily spoken at home		
English	12	100
Number of people living in household		
Mean	3	
Range	01–7	
Age (years) of person living with dementia		
Mean	82	
Range	62–101	
Gender of person living with dementia		
Female	6	50
Male	6	50

was “between” employment. All but two of the participants co-resided with their relative who had dementia. Of the 12 people living with dementia, six were woman and six were men. All had a confirmed diagnosis of dementia and ranged in age from 62 to 101 years, with an average age of 82 years. Table 2 summarizes the demographic characteristics of caregiver participants and their relative living with dementia.

Thematic Findings

We discuss our findings under three key themes that were brought up most by the participants reflecting the ways in which pandemic was most impactful on their daily lives. First, “Adopting and adapting to pandemic public health measures” was talked by all but one family repeatedly in their interviews as well as in diary reflections as the pandemic unfolded. This is a broad theme that encompassed subthemes of struggles of caregivers in (a) supporting their relative to follow social distancing rules; (b) maintaining safety with home support worker visits; and (c) buying supplies of masks and sanitizers and other essential supplies within a tight budget. Similarly, the second theme of “Erosion of formal and informal supports” was shared consistently by all participants except one signifying the impact the loss of such supports on their everyday lives. The third main theme, which was discussed by over two thirds of the participants, focused on the impact of the adaptations and loss of supports on their mental and physical well-being.

Adopting and Adapting to Pandemic Public Health Measures

Public health measures disrupted all aspects of the participants’ lives, and the prolonged nature of the pandemic and subsequent “waves” also meant that public health measures were continually changing. These measures required ongoing adoption and adaptations in everyday activities, which became a key theme of the study findings. After months of living with such measures, however, caregivers were hopeful they might be able to resume some semblance of in-person interaction; however, uncertainty over ongoing restrictions and the emergence of new variants created anxiety and left them wondering when life might return to “normal.” For example, in her third interview in April 2021, P01 shared,

But with that new variant [Delta] now, because we all thought, “okay, now things are going great, maybe we can get together, do the deck, sit six feet apart,” now it’s the new variant, it’s really hard. (when talking about being able to visit in-person with her daughter and son-in-law.)

A new role for caregivers was supporting their relative to follow public health measures. Wearing masks and hand-washing became part of everyday life during the pandemic but supporting a person living with dementia to follow these guidelines could be challenging, as described by P02, “the biggest issue is trying to get him to remember to wear his mask and not to hug people or shake their hands? He’s just got his hand out there” (Interview 3, April 2021). Changing lifelong social practices was a difficult aspect of public health measures, as was building mask wearing into their daily routines, as P02 went on to explain,

He's getting much better at remembering to at least put his mask on. I try to make sure that he's got one. He keeps a disposable blue one in his back pocket just in case he forgets and I forget to make sure he's got one. I try to keep some in the car.

However, the constant teaching and reminders regarding self-protection protocols further complicated daily routines and exacerbated caregiver stress. P02 noted, "Getting the hands washed and getting the mask off and then getting the hands washed again, all those things are difficult . . . it can be a bit of a trigger." As well, early in the pandemic stores limited the number of shoppers. P04 typically would have taken her husband along but needed to make arrangements with her neighbors to stay with him so that she could get groceries:

We live close to the shopping centre. It's just across the street. Going shopping, they all say, "well please only one person per household, right?" So, I have to run over. And I can do that, but I cannot stay away long. (Interview 1, November 2020)

Another facet of this issue was managing staff's adherence to public health measures when they came into the family's home. P10 described her set up in the home:

I always walk them to the sink to wash their hands when they come in. And I have paper towels available beside the sink. And I have Lysol wipes in the bathroom in case anybody has used anything in there. So, I think I've set up the house as best I can. (Interview 1, June 2021)

Because the staff were employed by the local health authority, they were provided with personal protective equipment (PPE) that they were expected to wear while inside client's homes. P10 went on to share what often happens:

Oftentimes one of the first things they'll ask you is, "Do you mind if I take the goggles off?" I don't particularly mind. But I would like them to keep the mask on. And it shocked me when I'd come home where they've had it down. I recognize like if you're doing crosswords and stuff, it can be hard to understand, but I've got other games. You can read, you can play Bingo, you know, whatever. But really, I don't think they have any business taking their masks off . . . I just ask them to put it back on, on their face.

Managing staff's use of PPE is another additional role for caregivers during the pandemic.

Getting vaccinated was an important pandemic milestone for families. Having endured limited social interaction with family and friends for many months, vaccinations offered caregivers an opportunity to return to some semblance of normality and safely engage with others. P02 described meeting friends outdoors, "we still are six feet apart and we bring our own coffee and our own chairs. But all of us, everybody has been vaccinated so we feel out in the breeze, we're probably okay" (Interview 3, April 2021). However, the local government's

decision to not vaccinate caregivers concurrently with people living with dementia did cause some concern. P03 described their experience during the vaccine roll-out:

I heard yesterday, they said, "a support person will get it at the same time." Yesterday they had a conference on the TV and said, "No, no, you have to wait your turn coming to your age." That took me kind of back . . . I mean you have somebody who is taking care of him and doesn't get the shot yet. (Interview 2, February 2021)

Caregivers described the additional economic burden of the pandemic measures. As P12 explained "I'm out there sourcing on N95 masks which are an arm and a leg when the pandemic starts, and getting the family and getting gloves, sanitizer and all this kind of stuff" (Interview 1, June 2021). There was also scarcity of supplies that they were already using, and now stores were limiting purchases or sold out entirely. She also shared how stores increased prices in response to pandemic demand:

I've been wiped on wipes. I've got a few for my parents who are low income. But [stores] all juggle in price. A lot of supplies started to go way up and some of those prices still haven't come down. (P12, Interview 1, June 2021)

This situation highlights one way in which pandemic response measures disproportionately impacted people with low incomes, who are often older people with fixed incomes.

The Erosion of Formal and Informal Supports

A second theme of the findings related to the erosion of formal and informal supports. In terms of formal supports, a major change at the outset of the pandemic was the abrupt closure of adult day programs. Many caregivers relied on day programs to provide respite, and also social interactions and routine for their relative. P04 used the word "salvation" to describe the role of the day program in her life, pre-pandemic, and further explained,

When the adult day care was on, see he was picked up in the morning by bus at 10:00 and he came back at 4:00 in the afternoon. So, all the time was free time, no worries for me about [relative], right? (Interview 2, February 2021)

However, it was not just existing clients who struggled with the absence of day program provision, but also potential new clients. P07 described how the ongoing shutdown of the local adult day program impacted both her husband and her: "[He] just needs to get into a day program. He really enjoys it. It doesn't matter what it is. He really enjoys it . . . He's so funny and you know, he loves being quick-witted." In the absence of the day program, her husband's attention turned to her "he's constantly looking for me all the time. Drives me

crazy” (Interview 1, April 2021). She went on to write more about her feelings about the situation in a diary entry:

I forget to take one day at a time when I get like this . . . I start feeling sorry for myself. Thinking why, why this is happening in my life now? I can’t stand watching the decline in this sweet funny man. I am tired of the constant attention he requires. . . where are the day programs that will give me a break? (P07, diary entry, June 2021)

Exhausted from the 24/7 demands of caring for someone living with dementia, the 15-month (to date) absence of day program services left caregivers feeling overwhelmed, unable to envision a time when they might receive the break they so desperately needed.

In addition to adult day program restrictions, ongoing health human resource challenges among home care providers also impacted families. P04 had been on a waiting list for in-home care for her husband since January 2021. She noted, “They say, ‘Well you’re on the waiting list.’ Because they have nobody. With COVID going on, they have hardly anybody that wants to work for them” (Interview 3, May 2021). Her husband was admitted into care in May 2021, without them ever having had a home care visit. In the absence of paid care providers, family caregivers were put in the position of taking on more of the hands-on personal care for their relatives:

I just never imagined myself being able to bathe somebody in all their private areas and yet here I am doing it because it’s a necessity. It has to be done. Somebody has to keep her clean. If she can’t do it for herself, somebody has to do it for her . . . (P01, Interview 1, November 2020)

The rapid expansion of virtual medical care has been a significant aspect of health care during the pandemic (Robinson et al., 2020). P09 described their experience with virtual care:

I think like the virtual doctor visits, on the one hand, you’re like, “oh, this is so much more convenient. I don’t have to go to the doctor’s office.” But on the other hand, like there is something about that immediacy of being in the same room as somebody that has been lost.

In this family’s situation, the physician caring for the person living with dementia changed during the pandemic:

Switching my dad’s doctor to a new doctor I think has been more complicated because of that. Like he’s not having that face to face with that person. So, it’s harder for him to like, establish a relationship with this new doctor. (Interview 2, July 2021)

In addition to formal supports (e.g., adult day programs, in-home staff support, medical appointments) changing, informal social supports were also transformed. Prior to

the pandemic, many families were involved in peer support groups. P10 described the value of these supports in their lives:

I belonged to all sorts of support groups prior to COVID, which all shut down. We used to go for coffee, to restaurants, we had spouses or significant others or parents or whatever. And it was wonderful to go out with people and know that if my husband or my mother wanted to eat with their fingers, nobody was going to touch us. (Interview 1, June 2021)

After the onset of the pandemic, these peer supports stopped meeting in person. Some organizations pivoted to providing supports via the telephone or online platforms, but this option did not appeal to everyone. As P05 explained,

They sent a Zoom thing saying “oh, if you want to be involved and do this and do that.” I just didn’t have the interest to involve with that. I’m not very technical. I don’t like to air my problems or concerns with other people that I may not know. I mean it’s one thing if it’s just a one-on-one or a couple of people and you know, myself. But when you have a bunch of them, it’s very difficult for me. (Interview 2, April 2021)

P05’s experience speaks to the importance of developing relationship and the level of trust required in such settings. COVID-19 made it so much more difficult to establish relationship at a time when caregivers really needed it most. Alternative forms of social interaction provided via online platforms like Microsoft Teams were also not always a satisfactory replacement for people living with dementia as P07 described: “I think [relative] was so bored with it yesterday, he got up and walked away” (Interview 2, June 2021).

Another type of pre-pandemic social support was getting assistance from other relatives, friends, and neighbors to care for the person living with dementia while the caregiver did errands or other activities. After the onset of the pandemic, caregivers were less likely to ask for this kind of help. P12 described, “we do have a couple of dear friends that in an emergency or a bind before COVID, you could ask . . . But now it’s difficult because you don’t want to put people in that position.” For P12, having an immune-compromised sibling and parent meant she was extremely fearful of anyone in the household contracting COVID, as it would mean the carefully crafted caregiving routines that she and her sister had set up would fall apart. As such, she was reluctant to have anyone enter the house, noting that, “. . . even our best friends and relatives we wouldn’t have in the house” (Interview 1, June 2021).

The pandemic also impacted participants’ friendships and typical social activities. P01 shared that her quilting group, which she described as “my social activity” had stopped meeting and changed to outdoor walking. However, she was concerned that public health measures would also affect that social activity (Interview 2, December 2020). Other families reflected on how the pandemic had altered their social

networks, “. . . during this pandemic we’ve closed everyone out. We never were super social people, our social network was small to begin with but now it’s so small” (P12, Interview 2, September 2021). Additional types of cultural and church-related activities were also stopped due to the pandemic and caregivers shared the loss of these social connections as well. In the next section, we illustrate how these shrinking social networks have impacted the mental health of both caregivers and people living with dementia.

Impact on Mental and Physical Well-Being

The cumulative impacts of adapting to public health measures and eroding supports, both formal and informal, had an impact on the mental and physical well-being of both people living with dementia and their caregivers, which is the final main theme of the findings. P04 described the change to persons living with dementia: “slowly they get all depressed too because they cannot go anywhere, they cannot have visitors” (November 2020). In a later interview in February 2021, P04 talks more about the impact on her husband’s mental health “And then he tells me every day he wants to die. ‘What’s the point of living? There’s nothing to look forward any more.’” P01 also shared her mother-in-law’s experience of trying to connect with other relatives by phone and how this impacted everyone:

there’s not a lot of phone calls to chat with her because she gets on the phone and she doesn’t know who they are. She has to keep asking. So, I always tell people, “Continue to call, don’t feel you can’t.” But I think it’s more frustrating for the family members thinking, “she doesn’t know who I am” and it might be upsetting to them. So, we don’t get as many phone calls. (Interview 3, April 2021).

Caregivers also felt strained by making decisions around balancing safety with the risks of accepting help. P12 and her sister, who share caregiving for their parents, at first restricted having paid staff inside their parents’ home. But after a period of doing all of their care, the sisters needed a break. However, the strain remained because of the perceived risk:

We are in a situation where now, with what happened recently and my dad’s progression, we need [outside help] and we have to kind of let down our guard. It’s anxiety-provoking but we have no choice if we want to keep ourselves healthy. But it does play on our health a bit because there’s the worry, right? (Interview 1, July 2021)

She went on to say, “you’re kind of torn between this pandemic and on the other hand wishing you could have people in [to help with care].” Many of the caregivers described their feelings associated with the burden of decision-making around risks for their relative.

Over time, the strain of social isolation was taking a toll on both caregivers and people living with dementia. In an interview in November 2020, P05 explained,

The big thing would be exercise classes in the gym. The big thing would have been going to the seniors’ centre and interacting there. Going to the thrift store, interacting there. Adult living, interacting there. All those things are gone. Their routines are gone. And anybody who is anybody will tell you that somebody with Alzheimer’s, they have to have a routine. They have to have something they’re comfortable with, that they enjoy, the same thing day in and day out.

Well, all that crap is out the window because of COVID. . . . Maybe it’s just having human contact. You know, like that’s the biggest thing. Right now, you feel like, you know, you’re a leper and that’s even harder for her because she’s a social butterfly and she’s . . . lost, you know.

Months later, in a diary entry, P05 shared the physical manifestations of their stress:

Experienced chest pain, called my doctor. He referred me to a specialist . . . I believe stress is a big part of my problems- worry, anxious, uncertainties. Each day has become very frustrating as this awful disease progresses. I feel much more hopeless and scared. But life must go on! . . . I believe that compound the awful disease with the many COVID restrictions and one can be consumed with stress and anxiety. (March 2021)

Discussion

The findings from our study illustrate the multi-faceted impacts of the pandemic and associated public health measures on caregivers and people living with dementia over time.

Data informing this article were collected over the course of a year and included 28 interviews and 34 diary entries from caregivers in 12 families. By following families over time, we learned about the issues they experienced during that period of the pandemic, as well as how these issues had a cumulative impact on the well-being of both people living with dementia and their caregivers. Throughout the pandemic, families needed to adopt and then adapt to changing public health measures. These included using personal protective equipment and social distancing, and in the case of caregivers, taking on a new role of supporting their relative living with dementia to also follow these measures. Families also experienced an erosion of formal and informal supports throughout the pandemic, which was shaped by public health measures (e.g., closure of day programs, social distancing from social network). The loss of these supports contributed to greater social isolation as well as shifting more care work onto family caregivers. Overall, the prolonged and somewhat unpredictable public health measures negatively impacted the participants’ mental and physical well-being over time. Our study meaningfully extends what is currently understood about the impact of the pandemic and related public health measures on community-dwelling people living with dementia and their caregivers in several ways. First, much of the existing literature in this area was conducted at one point in time, and by using a longitudinal approach our

study illustrates the cumulative impacts, particularly on mental and physical well-being. Second, the use of interpretive policy analysis contextualizes these experiences within the broader structural context and provides direction for policy and program development, which is the focus of the discussion below.

The continued closure or limited access to formal supports such as day programs and in-home supports has not only impacted participants at the individual family level but also has had implications for the health and social care systems. It is well documented that most people would prefer to die at home (Gomes et al., 2013). However, with the ongoing absence of formal supports and shift of care work onto families, there may be increased admissions to long-term care homes in the coming months and years. Organizations and funders ought to be considering innovative models of in-home support, such as direct funded home support where family caregivers have greater access to and autonomy to hire staff to provide support for persons with chronic conditions and disabilities, such as dementia (FitzGerald Murphy & Kelly, 2019; Hande & Kelly, 2015). These kinds of models allow families to identify and obtain the supports they need rather than relying on standardized and largely unavailable services and programs. The families in our study had different types of needs for in- or out-of-home supports for the person living with dementia. Innovative and flexible programs and services could meet their needs and support the person living with dementia to remain at home even as their disease progresses and care needs increase.

The pandemic has impacted all aspects of families' social and community lives as well. During pre-pandemic times, there was a growing movement to introduce Dementia Friendly Communities. While there are different types of these communities, common characteristics are that they promote a rights-based approach toward inclusive societies where people living with dementia are valued as full citizens. These communities focus on removing barriers to participation in everyday activities and promoting inclusion of people living with dementia (Buckner et al., 2019). For participants in our study, having this type of explicit community commitment could help to facilitate everyday—yet essential—activities during the pandemic such as grocery shopping. The introduction of Dementia Friendly Communities may be particularly helpful for families living in rural and remote areas, where there are already fewer formal resources for persons living with dementia (Wiersma & Denton, 2016).

The stripping away of many formal and informal supports, as well as adapting to ongoing and evolving public health measures over a prolonged period of time, has negatively impacted the mental and physical well-being of persons living with dementia and their family caregivers. Our study findings illustrating the physical, psychological, and emotional toll placed on family caregivers by pandemic-related changes are corroborated by studies that also highlight the fear, anxiety, stress, and isolation experienced by family caregivers of

people living with dementia during the pandemic (Sriram et al., 2021; West et al., 2021). Participants in our study also emphasized how the pandemic has resulted in the loss of continuity and a sense of normalcy for people living with dementia, and how these disruptions potentially hasten the progression of dementia. Recent studies have similarly shown how the loss of familiar and meaningful routines have significantly affected the psychological and cognitive well-being of people living with dementia, compounding the progressive decline inherent to the condition (Bacsu et al., 2021; West et al., 2021). The health impacts of the pandemic on community-dwelling people living with dementia and their family caregivers underscores the need for health and social care services to adopt a person-and-family-centered care approach, and create systems of mutual support between persons living with dementia, family caregivers, and professionals (Feinberg, 2014). Furthermore, given the limitations public health measures place on the provision of in-person supports, service providers are encouraged to consider alternative psychosocial interventions to strengthen caregiver well-being. For example, preliminary evidence suggests that mindfulness-based interventions (e.g., sitting/walking meditation, deep breathing, mindful movement, and visualization) have the potential to reduce stress, depressive symptoms, and anger and improve self-efficacy and quality of life over the short-term (Liu et al., 2017; Shim et al., 2021). Similarly, cognitive behavioral therapy interventions that focus on cognitive-reappraisal techniques, and self-care practices (Wiegelmann et al., 2021), and individual counseling sessions and telephone counseling at monthly intervals (Phung et al., 2013; Tremont et al., 2015) have also been shown to promote caregiver mental health through the reduction of depressive symptoms.

This study has limitations. Ten of the 12 caregivers who participated were women. While women are more likely to do care work, we did explicitly focus recruitment efforts on men and non-binary individuals in an effort to diversify gender representation. There was also limited diversity in relation to race and income. Although we sent regular reminders and offered other supports (e.g., compensation for their time and reimbursement for any costs associated with their time such as paying a care provider to be with the person living with dementia), there was variability in completion of the diary entries. Despite these limitations, given the consistency of our findings with previous cross-sectional studies, the results of this research are likely transferable to other jurisdictions.

Nurses working with families of people living with dementia in the community have a key role in mobilizing supports. In addition to the recommended actions already described above, nurses are well situated to assess the mental and physical well-being of caregivers over time as part of their ongoing presence with these families. Given that dementia is progressive, the needs of clients should be closely monitored as well as their caregivers' capacities to continue in a context where formal supports are seriously eroded. With the introduction of virtual health, there may be some aspects of an individual's

care needs that are not as evident in this delivery model, and nurses are well positioned to continue with in-home visits to assess disease progression and ensure caregivers are able to access available supports. At a more systemic level, collective advocacy is needed for the re-introduction of in-person community-based supports, such as day programs to ensure people living with dementia have the opportunity to engage in physical and social activities, and for caregivers to receive respite. Organizational leaders ought to ensure that these programs are operating safely and that practices are in place to avoid further closures.

In conclusion, our study provides insight into the long-term consequences of public health measures on community-dwelling people living with dementia and their family caregivers. The prolonged and unpredictable nature of the pandemic has impacted the physical and mental well-being of those receiving and providing care. The sustained isolation has left families feeling abandoned by both formal and informal support systems. Although much has been learned about the transmission of the virus, many services remain unavailable or are only available virtually. There is an urgent need to restart formal services, an action that family nurses are well positioned to lead.

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ORCID iDs

Jennifer Baumbusch  <https://orcid.org/0000-0003-3915-6881>
Heather A. Cooke  <https://orcid.org/0000-0002-3262-7989>

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Author Biographies

Jennifer Baumbusch, RN, PhD, is an associate professor in the School of Nursing at the University of British Columbia, Canada. Her areas of scholarship include family caregiving, long-term care, and dementia care. Her recent publications include “A Survey of the Characteristics and Administrator Perceptions of Family Councils in a Western Canadian Province” in *Journal of Applied Gerontology* (2022, with I. Sloan Yip, S. Koehn, R. C. Reid, & P. Gandhi) and “Family Members' Experiences and Management of Resident-to-Resident Abuse in Long-Term Residential Care” in *Journal of Elder Abuse and Neglect* (2018, G. Puurveen, D. Beaton, A. Phinney, M. D. Beaton, & M.-E. Beaton).

Heather A. Cooke, PhD, is a research associate in the School of Nursing at the University of British Columbia, Canada. Her areas of scholarship include long-term care, resident quality of care and quality of life, quality of staff work life, the role of family members, and dementia-friendly design. Her recent publications include “Residential Care Aides' Experiences of Workplace Incivility in Long-Term Care” in *Work, Employment and Society* (2021, with J. Baumbusch) and “Not Just How Many but Who Is on Shift: The Impact of Workplace Incivility and Bullying on Care Delivery in Nursing Homes” in *The Gerontologist* (2021, with J. Baumbusch).

Kishore Seetharaman, MS, BArch, is a PhD candidate in the Department of Gerontology, at Simon Fraser University, Canada. His areas of scholarship include environment, aging, disability, and design. His recent publications include the chapter “A Conceptual Framework of the Person–Environment Interaction in the Neighbourhood Among Persons Living With Dementia: A Focus on Out-of-Home Mobility” in *Dementia and Place: Practices, Experiences and Connections* (2021, with H. Chaudhury & A. Mahmood) and “‘I Am Making a Difference’: The Experience of Dementia Advocacy for Persons Living With Dementia in the

Community” in *Journal of Aging Studies* (2020 with H. Chaudhury).

Aneesha Khan is an undergraduate academic assistant in the School of Nursing at the University of British Columbia, Canada. Her areas of scholarship include health equity, women’s health, family studies, and patient care during visits to the emergency department.

Koushambhi Basu Khan, PhD, is a qualitative analyst in the School of Nursing at the University of British Columbia. Her areas of scholarship include health and health care inequities.