

Understanding the impact of the COVID-19 pandemic on well-being and virtual care for people living with dementia and care partners living in the community

Dementia
2021, Vol. 20(6) 2007–2023
© The Author(s) 2020



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1471301220977639
journals.sagepub.com/home/dem



Pamela Roach

Department of Family Medicine, University of Calgary; Department of Community Health Sciences, University of Calgary, Canada; Hotchkiss Brain Institute, University of Calgary, Canada; O'Brien Institute of Public Health, University of Calgary, Canada

Angela Zwiers, Emily Cox, Karyn Fischer and Anna Charlton

Department of Clinical Neurosciences, University of Calgary, Canada

Colin B Josephson

Department of Community Health Sciences, University of Calgary, Canada; Hotchkiss Brain Institute, University of Calgary, Canada; O'Brien Institute of Public Health, University of Calgary, Canada; Department of Clinical Neurosciences, University of Calgary, Canada; Centre for Health Informatics, University of Calgary, Canada

Scott B Patten

Department of Community Health Sciences, University of Calgary, Canada; Cuthbertson & Fischer Chair in Pediatric Mental Health, University of Calgary, Canada

Dallas Seitz

Department of Community Health Sciences, University of Calgary, Canada; Hotchkiss Brain Institute, University of Calgary, Canada; O'Brien Institute of Public Health, University of Calgary, Canada; Department of Psychiatry, University of Calgary, Canada

Corresponding author:

Pamela Roach, Department of Family Medicine, University of Calgary, G012 Health Sciences Centre, 3330 Hospital Drive NW, Alberta T2N 4N1, Canada.

Email: pamela.roach@ucalgary.ca

Zahinoor Ismail 

Department of Community Health Sciences, University of Calgary, Canada; Hotchkiss Brain Institute, University of Calgary, Canada; O'Brien Institute of Public Health, University of Calgary, Canada; Department of Clinical Neurosciences, University of Calgary, Canada; Department of Psychiatry, University of Calgary, Canada

Eric E Smith

Hotchkiss Brain Institute, University of Calgary, Canada; Department of Clinical Neurosciences, University of Calgary, Canada

on behalf of the **PROMPT Collaborators**

Abstract

The COVID-19 pandemic has necessitated public health measures that have impacted the provision of care for people living with dementia and their families. Additionally, the isolation that results from social distancing may be harming well-being for families as formal and informal supports become less accessible. For those living with dementia and experiencing agitation, social distancing may be even harder to maintain, or social distancing could potentially aggravate dementia-related neuropsychiatric symptoms. To understand the lived experience of social and physical distancing during the COVID-19 pandemic in Canada, we remotely interviewed 21 participants who normally attend a dementia specialty clinic in Calgary, Alberta, during a period where essential businesses were closed and health care had abruptly transitioned to telemedicine. A reflexive thematic analysis was used to analyze the interview and field note data. The impacts of the public health measures in response to the pandemic emerged through iterative analysis in three main categories of experience: (1) personal, (2) health services, and (3) health status (of both persons living with dementia and care partner). Isolation and mental health needs emerged as important impacts to family experiences. This in-depth understanding of the needs and experiences of the pandemic for people living with dementia suggests that innovative means are urgently needed to facilitate provision of remote medicine and also social interaction and integration.

Keywords

dementia, lived experience, COVID-19, well-being, virtual care, community

Introduction

With the emergence of COVID-19 (SARS-CoV-2) as a novel coronavirus in late 2019, a global pandemic has led to varying levels of social distancing restrictions across the world. This includes restrictions on public gatherings, the conduct of businesses, the accessibility of health care, and movement outside the home. Mandated public health measures in response to the pandemic increase the risk of social isolation with attendant consequences for well-being. Moreover, the rapid move to virtual care provision may influence how and when people access treatment from healthcare providers, in addition to how providers can continue to provide high-quality care in new virtual settings. In order to provide high-quality care that is grounded in patient experience, it is imperative

that we develop an understanding of the impacts of the pandemic and changes to well-being and healthcare provision from the perspective of people living with dementia and their care partners.

Current estimates suggest there are over 42,000 people living with dementia in Alberta (Alberta Health, 2017). In Canada, most persons with dementia (61%) live in the community (Canadian Institute for Health Information, 2018). Due to the nature of dementia, with changing abilities over time, people living with dementia and their families and care partners are already at risk for social isolation even in the absence of a new pandemic (Roach et al., 2016). Social isolation can be defined as the size of an individual's social network and the frequency of social contacts (Tilvis et al., 2012), both of which tend to decrease throughout the lived experience of dementia. Additionally, social isolation can increase risk of loneliness and therefore may also impact quality of life and the risk of morbidity and mortality (Luo et al., 2012). Social isolation is increasingly recognized to be detrimental to overall well-being (Vernooij-Dassen & Jeon, 2016; Ward et al., 2018). Maintaining well-being is a key component of person-centered dementia care (Kitwood, 1997) to ensure the ability to live well with a diagnosis of dementia. Well-being requires deep and meaningful human connections, health status above an expected baseline, positive interpersonal expectations, and a sense of self (Feeney & Collins, 2015). The unintended consequences of public health measures in response to the pandemic may include disrupted routines for many of the people living with dementia in the community, increased stress on care partners as they manage the demands of caring for someone living with dementia, and difficulty satisfying essential needs such as obtaining groceries and medications without the typical social and health service support or support from personal networks.

Multiple professional organizations including Alzheimer's Disease International (2020) have issued emergent COVID-related advice for persons living with dementia, but so far these recommendations have been based on little evidence, rarely collected systematically. To begin building an evidence base for the impact of the COVID-19 pandemic on well-being and health care of persons living with dementia, we conducted a qualitative study of persons living with dementia and care partners receiving community-based care at a dementia specialty clinic. Our objective was to determine the extent to which the COVID-19 pandemic and related public health measures impacted experiences of health care and well-being. Semi-structured, in-depth interviews using a qualitative approach were used to collect rich data on lived experience that incorporated a reflexive thematic approach to content analysis.

Research design

We completed remote, in-depth interviews using telephone with family members or care partners, as well as the person with dementia if they wished to and were able to provide consent. In order for participants to provide detail on the changes and impacts of the pandemic on their lives, it is important that these data are collected while the pandemic is occurring and while social distancing measures are in place.

Recruitment

We purposely recruited participants (people living with dementia and family members/care partners) who had attended the Cognitive Neurosciences Clinic in Calgary, Alberta, Canada, since January 1, 2019; had a diagnosis of dementia verified by a specialty neurologist or psychiatrist working in the clinic; were a participant in the PROspective Registry of Persons with Memory SyMPToms (PROMPT); and had previously provided written consent to be contacted about additional research. Snowball sampling was also used, with two dyads recruited this way, likely through a community network for younger people living with dementia. The primary care partner was identified by

clinicians during previous clinic visits and was initially approached for permission to participate in the study. The Calgary Cognitive Neurosciences Clinic operates out of two large tertiary care sites in Calgary, Alberta, Canada. It is the only dementia specialty clinic in Southern Alberta, with a catchment area of approximately 1.5 million. Patients are referred by a primary care provider and assessed for cognitive impairment and dementia by a staff of nurses and either a cognitive neurologist or psychiatrist. In Alberta, there is universal government funding for physician visits and diagnostic testing. PROMPT was established in the clinic in 2010 to investigate patient outcomes. Additional details on the PROMPT design have been published previously (Sheikh et al., 2018). All patients seen at the clinic are eligible to participate and enroll in PROMPT. Participation includes the opportunity to provide consent to be contacted for future research.

Consent was obtained using Qualtrics survey software (Qualtrics, 2019) or explicit oral consent from all participants, including the person living with dementia. The presence of a clinical research nurse on the team, familiar with the clinic population, meant that only people with dementia with capacity to consent and participate if they wished to were approached to consent to the study. Due to the nature of some of the clinic populations, explicit oral consent was necessary so that participants who wanted to participate but perhaps did not have access to the internet, e-mail, or who had disablements preventing them from using devices or computer screens could still be included. Explicit oral consent provided a way to ethically include a diverse population. Process consent (Dewing, 2007) was used throughout the project, where all participants provided verbal assent at every research encounter (including the initial call to introduce the project and any subsequent contact including interviews), to ensure that the participants were comfortable participating at that day or time. Options of telephone or Zoom interviews were used as a technological tool to complete the interviews in order to adhere to social distancing mandates put in place in the province of Alberta when the public state of emergency was declared on March 17, 2020. Potential participants were then contacted by telephone and informed of the project, after which information sheets and consent forms were emailed or mailed to interested participants who had a minimum of 24 hours to consider the information and discuss it with family members or health providers before providing consent to participate, and the interview is scheduled. This study was approved by the Conjoint Human Research Ethics Board at the University of Calgary (REB20-0559).

Data collection

In-depth interviews were used as they are an appropriate way to gain a robust understanding of lived experience and allow for exploration of topics that are important to the participant, maintaining a participatory approach to working with people living with dementia and care partners. An interview guide was created asking general questions about experiences of isolation due to the pandemic and virtual healthcare experiences and was tested and updated after the first two interviews to act as pilots. It was anticipated that theoretical saturation of participant experiences would be achieved after completion of 15–20 interviews and so a target of recruiting 20 participants was initially determined. In-depth interviews were audio recorded and field notes were taken during the interviews in a dedicated field journal, along with reflexive field notes written directly after the interviews. Demographic data were also recorded and was available through the current registry, and information on whether the participants had contracted COVID-19 or were tested for SARS-CoV-2 was collected by interview. To collect the planned sample size of 20 completed interviews, we contacted 45 people of whom 21 consented and completed the interview. Interviews ranged in duration from 8 m:33 s to 34 m:38 s (mean length = 21 m:12 s), and all interviews were completed over the phone as per participant request. Interviews were conducted between April 23 and May 21,

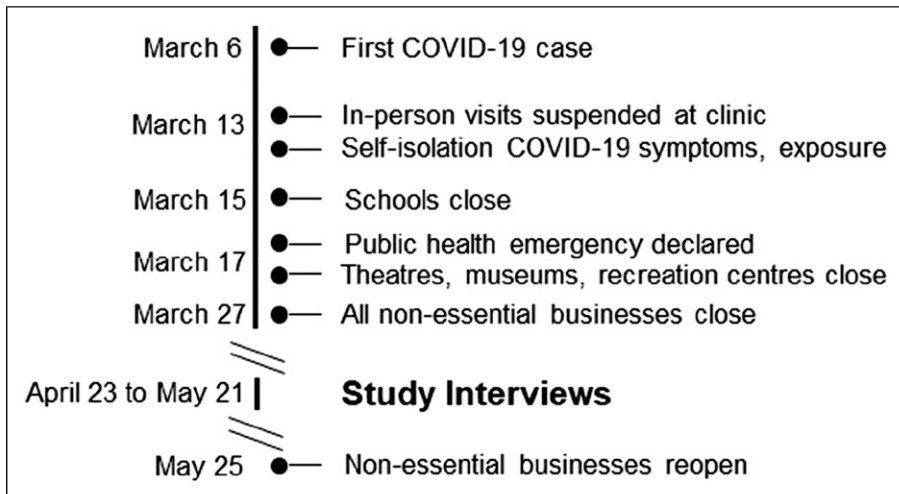


Figure 1. Time line of COVID-19 public health response in Alberta, Canada.

2020, with recruitment and data collection completed by [KF], [AZ], and [EC]; all research staff were with experience of working with people living with dementia, ranging from 3–18 years, and directed by the lead author who has been working with people living with dementia and families for over 14 years. The interviewers were unknown to the participants at the time of interview but introduced themselves and the reason for the work at initial contact and at the time of interview. All consent forms and transcripts are held on a secure, password-protected shared drive and accessible only by the Principal Investigator and the research team.

In Canada, provincial governments are primarily responsible for implementing public health measures for pandemics. A time line of provincial measures for social distancing and health system reorganization was created by review of public records of the City of Calgary and government of Alberta, communications from Alberta Health Services (the single public healthcare system in Alberta that manages the Cognitive Neurosciences Clinic), and the Calgary Herald newspaper (Calgary, Canada). From March 4 onward, the provincial Chief Medical Officer of Health conducted daily briefings on virus activity and the government response. The Cognitive Neurosciences Clinic ceased routine in-person visits on March 13 and virtual care appointments for the regular attendees of the Cognitive Neurosciences Clinic were implemented on March 14, 2020. A time line of public health measures implemented by the Government of Alberta is shown in [Figure 1](#).

Analysis

Audio recordings were transcribed verbatim using a secure professional transcribing service and anonymized and verified by the research team. All names, physician names, and identifying details were removed to protect the confidentiality of the participants. Transcripts and field notes were managed using NVivo 12 ([QSR International, 2018](#)) for the qualitative analysis and data management. Interviews were transcribed concurrently while data collection was still occurring so that generated themes could be discussed at subsequent interviews to achieve theoretical saturation. Immersion in the qualitative data was the first step of data analysis. Transcripts were read and reread while the interview recordings are replayed. A reflexive thematic analysis ([Braun et al., 2016](#); [Clarke et al., 2019](#)) was used to analyze the interview and field note data. Reflexive thematic analysis

positions the researcher as a mechanism in the production of the analysis. This form of iterative analysis also requires a cognizance of theoretical assumptions that centers the experience of the person living with dementia and care partner and their experiences within the data and the analytical process. Analytical thoughts and iterative analyses were captured using memos and annotations. Disagreements over analyses and emergent themes were resolved via team discussion. Themes and subthemes were brought back to the participants for member checking and to enhance qualitative rigor and establish trustworthiness of the data (Lincoln & Guba, 1985).

Results

Participant demographics

There were 20 dyads of persons living with dementia and care partners; in 18 cases, the persons living with dementia declined to participate but the care partner participated and in one case, the person living with dementia and care partner each participated on their own. Diagnoses and last Folstein Mini-Mental Status Examination (Folstein et al., 1975) scores for the persons with dementia are shown in Table 1.

No participants reported a diagnosis of COVID-19 for anyone living in their household; two care partner participants suspected they may have had COVID-19 due to symptoms but were not tested; and a third care partner participant reported being told to isolate due to being in a high-risk group of complication from COVID-19.

Thematic analysis: Experiences of the COVID-19 pandemic

Through the completion of the qualitative analysis with coding and synthesis completed by [EC], [AZ] and directed by [PR] (Principal Investigator and qualitative methods expert), three overarching themes emerged from the data (see Table 2) that clearly demonstrated the impact of the COVID-19

Table 1. Characteristics of the 20 persons living with dementia who were interviewed or whose care partner was interviewed.

| Characteristic | Value |
|-----------------|-------------------------------|
| Age (mean, SD) | 69 years (SD 8.3) |
| Female sex | 10 (50%) |
| Diagnosis | 15 (75%) |
| | AD |
| | Frontotemporal |
| | Mixed AD/vascular |
| | Mixed AD/frontotemporal |
| | Psychosis, suspected dementia |
| | Not specified |
| Severity | Mild (MMSE 20 or above) |
| | Moderate MMSE 13–19)* |
| | Severe (MMSE 0–12) |
| | Unknown** |
| Time since MMSE | Median 12.7 (IQR 6.0–22.5) |

AD: Alzheimer's disease; IQR: interquartile range; MMSE: Folstein Mini-Mental State Examination; SD: standard deviation.

*Includes one person with blind Montreal Cognitive Assessment score 12 out of 22. **A participant recruited by snowballing, without ability to link to clinic registry data.

Table 2. Experiences of the COVID-19 pandemic.

| Theme | Subtheme |
|--|--|
| Personal impact of public health measures | Personal support Managing day-to-day activities |
| Health services impact of public health measures | Home care services and support Community programming Virtual medicine: Barriers and facilitators |
| Health status impact of public health measures | Anxiety and mental health concerns Social distancing and cognitive decline Care partner burnout |

pandemic on experiences of cognitive neuroscience patients and their care partners. The themes built on a coding tree that started with small, descriptive codes about discrete areas of day-to-day life and were then synthesized to larger descriptions of experience. These themes are described in more detail below and have edited only for general grammar and spelling to enhance readability.

Personal impact of public health measures

Personal support. Participants noted significant changes in their experiences of social support during the pandemic. Social and physical distancing, as enacted by public health measures, meant that the normal informal family and community supports were limited.

“So basically, being confined to the home, in general. Obviously, at the start the weather also wasn’t great, so, basically, the combination of, you know, bad weather, being... completely confined to the house, and then basically, the social isolation for my mom personally, that has been the biggest toll for her.” (Participant 124; Care Partner)

“There’s, there’s no method to cope. I can’t ask people, family to come and help me. I can’t, there has been nothing I can do. No, I have not found anything for me personally that has been good about it. I have not been able to go to work. I have no socialization. I’m just left to cope on my own.” (Participant 141; Care Partner)

It was also clear that the informal support provided by the community or by family members was crucial for many people who were anxious or afraid to leave the house for essentials. Those participants who had family support reinforced these messages.

“The first time we did something at the superstore, we put in a pick-up order. I don’t have a cell phone. I have a computer but not a cell phone. So my daughter said ‘You know, you put your order in and then I’ll go over and pick it up when it’s ready.’ She would do that for me. And we social distanced the whole time, like she’d drive up in the driveway.” (Participant 123; Care Partner)

Managing day-to-day activities. Many care partners reported stress around coping with day-to-day activities of living and some of this stress was due to no longer having the formal home care service they had been receiving before the pandemic and shut down of services.

“That’s when I got him to take a bath as well. But it was a long time. I still have to coax him. He’s been changing... like, I’ve ironed clothes for him the other day... But he’ll just put on whatever and then he’ll wear it for days...” (Participant 115; Care Partner)

“I don’t know that we are coping that well. (laughs) Um, there really was nothing I can do. I’m just trapped at home with him. I’m trapped at home.” (Participant 141; Care Partner)

“I think probably one of the biggest challenges for my husband because of his cognition is the social distancing part. We had friends that sat about ten feet away and we were on the other side of our deck. And so when they came he was automatically wanting to go up and greet them and shake his hand... So I think sometimes it’s, the social distancing ... Um, I don’t know. I think with the level of cognition that, uh, some days my husband has said it’s a foreign concept - like social distancing... I would not say that he understands that.” (Participant 106; Care Partner)

Health services impact of public health measures

Healthcare services and support. The personal impact of the pandemic and associated public health measures is closely associated to the health services impact of these same measures. Participants reported feeling alone and unsupported in many cases and were largely understanding of the need for health services to focus on the pandemic response. It was also clear, however, that some degree of ongoing contact was crucial for continuing to support families living with dementia.

“That’s kind of what I feel is, ‘You’re just on your own.’ ...I haven’t heard from anyone. I finally phoned someone the other day and ‘Yeah. Well people in AHS [Alberta Health Services] have been redeployed’, etc. etc., which is just fine. So maybe it would have been helpful if like your caseworker, somebody just to check in. Yeah, for sure.” (Participant 105; Care Partner)

“Well, there’s nothing much because right now home care isn’t coming into the home. So the one on one, you know, he’s not getting that. If that was still happening I think that would be a huge help. But, it’s not and I can’t, you know, I totally understand and I don’t begrudge it. I want everybody to be safe but it is a very isolating, difficult time.” (Participant 103; Care Partner)

One person living with dementia expressed that they did not feel a lot of anxiety about going to their physician in person; however, they would like to use a mask but were unsure how to get one. At the time, Alberta’s mask distribution strategy was to give out free masks to people driving through coffee and fast food outlets. This strategy may not have been effective at reaching persons living with dementia, highlighting that at-risk age groups and people with underlying health conditions such as dementia need to be better considered in future planning for distribution of personal protective equipment.

“The only thing I would like... I’d like to get a hold of those masks... I don’t know how you go about that. I might go just to [Tim] Hortons or something with my son...but I don’t go inside... we’ve got a little Hortons at the end of our block here and it’s not a very big one. But I never go inside...” (Participant 108; Person living with dementia)

Some participants did report formal service and community programming continuing to stay in contact and support families in innovative ways, and this continued contact was appreciated, even

if the service level and model delivery had changed when the program had to stop in-person programming.

“He goes to an adult day program on Wednesdays through [program]. They have been fabulous. Absolutely fabulous. They’re very good. They phone to see if we need groceries or anything at all because they’re willing to do it. And then tomorrow they said they were going around to all the clients and delivering baking. Every day of the program we always hear from them. Over the phone. Yeah.” (Participant 111; Care Partner)

Virtual medicine: Barriers and facilitators. Due to the scale of immediate shift to social and physical distancing, healthcare providers and patients had to quickly adapt to remote delivery of care in a virtual medicine format. Overall, many participants expressed that although they prefer face-to-face appointments with their care team, there were perceived advantages to receiving care in a remote format. These included not feeling as rushed, having options presented such as telephone versus zoom, and care partners expressed an ability to be more candid with the doctor if the person living with dementia was not participating in the call.

“And that was... we felt that that was good. My husband wasn’t part of the conversation because we were discussing some test results. We asked, I did ask my husband if he wanted to be part of the conversation or if he was comfortable that I would relay the information. And so, um, because he chose to not be part of the conversation, the doctor and I could be a little more candid.” (Participant 106; Care Partner)

“But the conversation was very good because we both had time to ask questions, answer the questions, and I would say my doctor probably, hopefully, didn’t feel rushed. And I didn’t feel rushed. And I think that part was very much a bonus.” (Participant 106; Care Partner)

“It’s going to be over Zoom. Oh, we had one yesterday with [nurse]. Did, a bunch of testing yesterday and that worked just fine. Actually I think it worked out great. He was able to do the drawings and then hold the paper up and show her- I think it worked fabulous.” (Participant 129; Care Partner)

Conversely, care partners did also report that if the person living with dementia was in the room or wanted to be part of the call, there was less opportunity for frank one-on-one conversations with the doctor and that this could be potentially distressing for the person living with dementia, depending on the nature of the discussion. Participants also expressed some concern with technological barriers of connecting via internet, and while recognizing that body language and nonverbal communication was important to the appointment, support is necessary for people who are unfamiliar with the technology to be able to fully participate in this way.

“...for this next month, I’ve actually written a letter and I put it on a spreadsheet. I’m hoping I don’t have to go over it verbally with him [the doctor] and he can read the spreadsheet and then we can talk about it.” (Participant 143; Care Partner)

“Like my mom had a follow up, uh, doctor’s appointment that was, at least they’re gonna do it on the phone as opposed to on a Zoom session. Because I hear this from my dad a lot, it’s like, you know what? Everybody wants to do all this stuff online and, I mean, some, some seniors capability of using computers is a little more limited.” (Participant 126; Care Partner)

Health status impact of public health measures

Anxiety and mental health concerns. Participants described feeling anxiety about the pandemic in general and about needing to leave the house, both personally and perceived anxiety on the part of the person living with dementia. This highlights the need to be cognizant of increased mental health needs for cognitive clinic patients and family members in times of social and physical distancing.

“Well, I do find that he is definitely more anxious and worried and fearful, but I have no idea if that’s related. I doubt that it is. I imagine that it’s more just a progression of the dementia.” (Participant 105; Care Partner)

“Well now on the phone, he’s asking me the same questions and [Person living with dementia]’s right there with me because that’s what he wants. And so that was awful...because [Person living with dementia] gets very upset when we talk about stuff...” (Participant 143; Care Partner)

“Yeah, and it’s so difficult... That taught me a lesson. So we went out. I couldn’t leave it, so I have to go pick it up today. And that’s frustrating because that gives you more anxiety of just leaving the house. I don’t have trouble leaving the house, but if [Person living with dementia] comes with me he has to wait in the car. And then, it was just really stupid of me. I said my brain’s going under too, a huge thing. Nothing’s in sync.” (Participant 111; Care Partner)

Social distancing and cognitive decline. A number of participants also expressed concern that the person living with dementia was experiencing more cognitive decline since the start of the public health measures during the COVID-19 pandemic. These concerns were focused around the decrease in social interaction impacting the progress and severity of cognitive decline, which was perceived as progressing more rapidly the previous 2 months.

“I mean, my mom didn’t have great recollection of going to [day program], I recall. Like when I’d visit her she’d vaguely remember doing stuff. I don’t know if it provided a different level of stimulus because I seem to have noticed a little bit more of a... kind of slow decline or decay... Where maybe it’s not getting the same activity now. Um, so noticing a slight decline in her cognition... I mean if the decline is a slope, the slope’s a little bit steeper in the last couple months than it was...” (Participant 126; Care Partner)

“Her [centre] program was something that I think she really thrived when she was going there, especially I noticed, you know, mood improvement, sleep improvement, all of those types of things. The more activity that my mom is doing... the better off. She was swimming every Saturday before this. Now, I feel like with changes that have kind of happened, those types of things, I think, will be hard to get back into that type of an exercise environment, which sucks because that was something that if you keep in the routine and don’t change, then I think it could have gone on for a lot longer. I think with the decline that’s kind of happened over the past five weeks, those types of things will have to be removed, unfortunately. I found that, in the past five weeks, her telephone skills have, like, literally disappeared. That is non-existent. She was able to pick up the phone and, you know, say ‘Hello’, all that kind of stuff, non-existent now.” (Participant 124; Care Partner)

Care partner burnout. Many care partners expressed feeling as though they could not cope on their own, with limited access to both formal and informal supports. The changes to the health systems and services provided described in the section above have effects on the amount of burnout

expressed by family members and care partners. Participants also worried about returning to work if the services that enabled them to do, so pre-pandemic were not reinstated.

“Well, I don’t know how it works with social distancing, but I am, we have had quite a decline. I’m not saying it’s from this social distancing, but there’s been a marked decline... I’m on the verge of asking for someone coming in despite the fact that we’re in social, you know, it’s been a lot. It would be helpful if they could, I guess ease up and have a visitor come around once a week or something and have some time where you just had an hour when you weren’t on... on call 24/7.” (Participant 143; Care Partner)

“My father’s providing primary care duties and they’re in their 80s type thing. One of the key things that’s changed is that my mom used to go to day program twice a week that gave my dad some respite and that kind of obviously stopped. So that’s put more stress on him because he’s not getting that relief type thing. And my dad doesn’t have a big social network to begin with and, uh, that’s been restricted by the, the kind of public health measures and, and the social distancing. And, uh, that’s made things more difficult. I mean, he’s doing the primary caregiving. Um, he’s doing all the, the kind of, there’s, there’s no rest but he’s doing all the work at home in terms of meal preparation, things like that... that’s put a lot of stress on my dad. He’s not been given a lot of great resources.” (Participant 126; Care Partner)

“I lost all my support. All of it, except for a few hours. So I was just left to just manage this on my own. Yeah... you know, it, going from, you know, 24 hours of day program and 35 hours of home care to nothing. They stripped all my support away... Yeah. Like, I am scheduled to start going back to work again and no one, no one can tell me what I’m supposed to do with my spouse, because the day programs are no longer active. So for 24 hours a week now I don’t know what I’m supposed to do.” (Participant 141; Care Partner)

Discussion

This study provides early evidence of the impact of COVID-19 on persons living with dementia and their care partners. These interviews identified multiple adverse consequences of the public health measures implemented to contain spread of SARS-CoV-2, including loss of informal caregiving, lack of access to health care, and social isolation, contributing to burn out symptoms among care partners. This validates the concerns expressed by multiple advocacy organizations (such as the Alzheimer Society of Canada, Alzheimer’s Association (USA), and Alzheimer’s Disease International), which although well founded have nonetheless been based on anecdotes or speculation without data collected directly from persons living with dementia. Our data were collected during a period of “lockdown” when all nonessential businesses were closed, health clinic access was mandated to be online or telephone except for emergencies, and most in-person home care services were no longer being provided. Therefore, it provides a snapshot of the adverse effects of the aggressive public health efforts that were needed to “flatten the curve” to prevent health system collapse. These drastic public health measures, while being lightened in many jurisdictions, may yet be required in other countries at an earlier stage of the pandemic or in case of a second wave of viral infections in the Northern Hemisphere in the fall.

So far, there are few data on the impact of COVID-19 on dementia care even though it is well understood that older people with medical comorbidities are at much higher risk of fatal infection. In a letter in the *Lancet*, physicians from Wuhan province cited multiple barriers to good dementia care including difficulty adhering to social distancing and good hygiene, loss of services, and difficulty accessing telemedicine (Wang et al., 2020). However, no perspective from persons living with

dementia or quantitative information was included. A hospital-based cohort from Italy noted that patients with COVID-19 infection with a history of dementia were more likely to die and often presented with hypoactive delirium (Bianchetti et al., 2020). A quantitative survey study of community-dwelling persons with mild cognitive impairment or mild dementia in Spain reported overall good mental health (Goodman-Casanova et al., 2020). However, that study used a quantitative survey without open-ended questions, did not include care partners, and was limited to persons with mild dementia. In contrast, this study elicited many serious concerns particularly among care partners of persons with more moderate to severe dementia.

We identified multiple impacts on well-being of people living with dementia and their family members and/or care partners. Although most participants understood the need for social distancing, they found it difficult both physically and emotionally. Meaningful activity and social engagement are vital to the well-being and functioning of families of persons living with dementia (Phinney, 2006; Phinney et al., 2007; Roach & Drummond, 2014; Roach et al., 2016). Care partners expressed concerns that cognitive decline accelerated during social distancing. This is consistent with literature finding that loneliness can be detrimental to well-being and quality of life (Moyle et al., 2011) and increase the risk of mortality and morbidity (Luo et al., 2012; Tilvis et al., 2012). Social interaction can be beneficial for cognitive functioning (Vernooij-Dassen & Jeon, 2016) and so it is plausible that social isolation could provoke accelerated cognitive decline and or an exacerbation of neuropsychiatric symptoms of dementia.

The adverse impact of the COVID-19 pandemic on mental health is increasingly recognized (Armitage & Nellums, 2020; Holmes et al., 2020). These mental health impacts may be compounded when care partners no longer have access to formal and informal supports that provide respite and increase resilience for care partners help with hygiene, medication, day-to-day activities of living, and essential tasks such as shopping for groceries or collecting medications. Moreover, the challenges of assisting a person living with dementia to navigate changing public spaces where physical distancing, wearing of masks, and controlled movements are necessary lead to additional stress for the care partner and greater risk for the person living with dementia.

Participants were understanding these measures but at the same time expressed concern for their own ability to continue to cope on a long-term basis, and the possibility of burnout without these supports. This echoes general concern of burnout by families living with dementia in times before the COVID-19 pandemic (Brodaty & Donkin, 2009; Sörenson & Conwell, 2011; Takai et al., 2009), but with these caring demands now amplified by isolation and anxiety. People living with dementia and care partners were at increased risk of isolation before the pandemic (Luo et al., 2012), and the additional risks with increased isolation, resulting loneliness, and physical and mental health comorbidities have relevance for both lived experience and health system delivery. With the accompanying sudden shift to virtual care by almost all healthcare teams, there was additional anxiety experienced with regard to the availability of care and how to access it, including how to obtain personal protective equipment, like nonmedical masks, to wear in public. Public health policies to distribute equipment to vulnerable sectors of society equitably are important to consider when developing these strategies.

Many of the stresses and anxieties identified in this study could potentially be mitigated through health system innovations. Remote support for social interaction for people living with dementia and care partners should be explored. There is evidence that tablet-based interventions can benefit cognition and self-perceived quality of life for people living with dementia (Hung et al., 2020; Kong, 2020), and ongoing work is being made with integrating social robots into the care of people with dementia in the community (Hung et al., 2019; Korchut et al., 2017). Rapid implementation of these innovative technological solutions may provide one strategy to increase social interaction and improve well-being in times of pandemic public health restrictions. Additional evidence is needed to

demonstrate what kind of interaction may be valuable for these approaches and what types support may be most facilitative of a protective effect for cognition (Kim et al., 2015).

Other possible remote support for people living with dementia and families include virtual social networking, including virtual dementia cafes or day programming moving to online interaction (Hung & Mann, 2020). Where this is not possible, telephone check-ins may also prove to be a valuable source of support for the mental health and needs assessment for families. The more problematic question remains focused on remote approaches to care partner respite, which is difficult to navigate during times of public health restrictions. Possible solutions for home care or social care workers may include scheduled home care visits incorporating walks where the formal care provider and person living with dementia maintain an appropriate social distance, meal or medication collection and delivery at a safe distance or with the appropriate personal protective equipment, and flexibility on maximum limits for dispensing medications to reduce the number of needed trips to the pharmacy. Finding innovative ways to continue to provide care partner respite and social connection via safe face-to-face and virtual means must become a priority for health and social care provision.

Delivering high-quality telemedicine will be essential to ensure good health during a time of social distancing. It was evident in the data that if patients and care partners are expected to connect with internet technology, clear guidance should be provided to explain how to set up and use technology that may be unfamiliar to many. The ability for a care partner to provide confidential information to a clinical care team in advance of a scheduled virtual appointment was also expressed, particularly when the care partner wished to notify the medical team of symptoms that are potentially distressing or humiliating to the patient, or could lead to conflict. To address this need, our clinic is implementing secure web-based surveys that will allow the care partner to confidentially report neurobehavioral symptoms, function, and caregiver burden, using validated scales, with separate telemedicine appointments with the care partner as necessary. This work leverages data systems employed to capture patient data in the PROMPT registry, demonstrating another use of clinical patient registries for meaningful patient engagement and service improvement. Previous work has shown that neurological and psychiatric patient populations do not see registry participation as burdensome but as an altruistic way to contribute to research that may or may not also provide personal benefit (Lee et al., 2019). Enhancing communication and preparation for clinic appointments has been shown to improve health outcomes in non-pandemic times (Entwistle & Watt, 2006; Street et al., 2009), and we can reasonably extrapolate that this would be true during times of social and physical distancing as experienced during the COVID-19 pandemic.

Strengths and limitations

Strengths of the study include that it was embedded in a prospective clinic registry which enabled us to quickly contact people living with dementia and their care partners during the COVID-19 pandemic and link their data to physician collected information on cognitive assessment and disease diagnosis. The main limitation is that the study was conducted in a single setting, a specialty outpatient dementia clinic, in an urban location with universal health care. It may not be wholly applicable to persons receiving care in family practices or with limited access to care. In future work, we will also work to include more people living with dementia in the interviews, and perhaps the necessity of remote interviewing in this study presented a barrier to communication. However, the themes that emerged from our work accord with the concerns expressed by multiple advocacy groups, expert opinion (Brown et al., 2020), and the early observations of dementia specialists in Wuhan province (Wang et al., 2020); therefore, we expect that most of the themes are universal and not idiosyncratic to our practice setting. By design, we did not include persons living with dementia who are residing in care

homes or who are hospitalized in acute care; additional research is needed on these important populations. This work is limited to the impacts of the initial public health response to the COVID-19 pandemic, and it will be useful to continue additional qualitative work to better understand the impact on different groups over time as the public health response evolves and society adapts to the changes.

Clinical implications

This in-depth understanding of the lived impact of decreased social engagement and healthcare access on personal well-being can inform future health and social policy and health service provision as described throughout the discussion. This knowledge may be useful for future pandemics (including the observed resurgence of COVID-19 in the fall of 2020 and winter of 2021), extreme weather phenomenon, outbreaks of other disease or isolation in supportive living or long-term care facilities, or other emergencies where social distancing/isolation/virtual care may be required. The reported increase in neuropsychiatric symptoms is also important for treatment planning and support in times of social distancing. Improved and innovative approaches to remote care and virtual medicine, including flexible mental and social supports for families, and the ability to provide information to clinical care teams prior to remote medical appointments have the potential to facilitate high-quality patient care that meets the needs of families and patients.

Acknowledgements

The PROMPT registry is funded by the Katthy Taylor Chair in Vascular Dementia of the University of Calgary, with support from the Brain and Mental Health Research Clinics Initiative funded by the Hotchkiss Brain Institute, Department of Clinical Neurosciences, and Department of Psychiatry at the University of Calgary. The PROMPT Collaborators are: Drs. Eric Smith, Zahinoor Ismail, Dawn Pearson, Aaron Mackie, Alicja Cieslak, Brienne McLane, Bijoy Menon, Dallas Seitz, David Patry, Phil Barber, Robert Granger, David Hogan, and Collen Maxwell.

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: This work is supported by an award from the University of Calgary Cumming School of Medicine COVID Rapid Response Clinical Research Fund (Grant number: CRF-COVID-202003). Direct and in-kind funding was also provided by the Brain and Mental Health Research Clinics, a part of Hotchkiss Brain Institute (<https://brainandmentalhealthclinics.ca/>).

ORCID iDs

Pamela Roach  <https://orcid.org/0000-0001-7694-9309>

Scott B Patten  <https://orcid.org/0000-0001-9871-4041>

Zahinoor Ismail  <https://orcid.org/0000-0002-5529-3731>

References

Alberta Health, Continuing Care. (2017). *Alberta dementia strategy and action plan*. Government of Alberta. <https://open.alberta.ca/dataset/772005d6-94f8-4a62-a39b-cc91265f3fca/resource/40959fbb-ca1d-4b44-8864-f05e8d1c6d0f/download/alberta-dementia-strategy-and-action-plan.pdf> (accessed August 24, 2020).

- Alzheimer's Disease International. (2020). ADI offers advice and support during COVID-19. <https://www.alz.co.uk/news/adi-offers-advice-and-support-during-covid-19> Accessed May 29, 2020.
- Armitage, R., & Nellums, L. B. (2020). The COVID-19 response must be disability inclusive. *The Lancet Public Health*, 5, e257.
- Bianchetti, A., Rozzini, R., Guerini, F., Boffelli, S., Ranieri, P., Minelli, G., Bianchetti, L., & Trabucchi, M. (2020). Clinical presentation of COVID19 in dementia patients. *The Journal of Nutrition, Health & Aging*, 24, 560. DOI: [10.1007/s12603-020-1389-1](https://doi.org/10.1007/s12603-020-1389-1).
- Braun, V., Clarke, V., & Weate, P. (2016). Using thematic analysis in sport and exercise research. In: B. Smith & A. C. Sparkes, (Eds.), *International handbook on qualitative research in sport and exercise* (pp. 191-218). Routledge.
- Brodsky, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, 11(2), 217-228.
- Brown, E. E., Kumar, S., Rajji, T. K., Pollock, B. G., & Mulsant, B. H. (2020) Anticipating and mitigating the impact of the COVID-19 pandemic on alzheimer's disease and related dementias. *The American Journal of Geriatric Psychiatry*, 28, 712. DOI: [10.1016/j.jagp.2020.04.010](https://doi.org/10.1016/j.jagp.2020.04.010).
- Canadian Institute for Health Information. (2018). *Dementia in Canada*. <https://www.cihi.ca/en/dementia-in-canada> Accessed August 25, 2020.
- Clarke, V., Braun, V., Terry, G., & Hayfield, N. (2019). Thematic analysis. In: P. Liamputtong, (Ed.), *Handbook of research methods in health and social sciences* (pp. 843-860). Springer.
- Dewing, J. (2007). Participatory research. *Dementia*, 6, 11-25.
- Entwistle, V. A., & Watt, I. S. (2006). Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient Education and Counseling*, 63, 268-278.
- Feeney, B. C., & Collins, N. L. (2015). A new look at social support. *Personality and Social Psychology Review*, 19(2), 113-147.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state. *Journal of Psychiatric Research*, 12, 189-198.
- Goodman-Casanova, J. M., Dura-Perez, E., Guzman-Parra, J., Cuesta-Vargas, A., & Mayoral-Cleries, F. (2020). Telehealth home support during COVID-19 confinement for community-dwelling older adults with mild cognitive impairment or mild dementia: Survey study. *Journal of Medical Internet Research*, 22, Article e19434. DOI: [10.2196/19434](https://doi.org/10.2196/19434).
- Holmes, E. A., O'Connor, R. C., Perry, V. H., Tracey, I., Wessely, S., Arseneault, L., Ballard, C., Christensen, H., Cohen Silver, R., Everall, I., Ford, T., John, A., Kabir, T., King, K., Madan, L., Michie, S., Przybylski, A. K., Shafran, R., Sweeney, A., ... Bullmore, E. (2020). Multidisciplinary research priorities for the COVID-19 pandemic: A call for action for mental health science. *The Lancet Psychiatry*, 7, 547-560.
- Hung, L., Berndt, A., Wallsworth, C., Horne, N., Gregorio, M., Mann, J., Liu, C., Woldum, E., Au-Yeung, A., & Chaudhury, H. (2019). Involving patients and families in a social robot study. *Patient Experience Journal*, 6(2), 66. DOI: [10.35680/2372-0247.1362](https://doi.org/10.35680/2372-0247.1362).
- Hung, L., Chow, B., Shadarevian, J., O'Neill, R., Berndt, A., Wallsworth, C., Horne, N., Gergorio, M., Mann, J., Son, C., & Chaudhury, H. (2020). Using touchscreen tablets to support social connections and reduce responsive behaviours among people with dementia in care settings: A scoping review. *Dementia: The International Journal of Social Research and Practice*. DOI: [10.1177/1471301220922745](https://doi.org/10.1177/1471301220922745).
- Hung, L., & Mann, J. (2020). Virtual special issue – Using touchscreen tablets for virtual connection. *Dementia: The International Journal of Social Research and Practice*, 19(5), 1346-1348. DOI: [10.1177/1471301220924578](https://doi.org/10.1177/1471301220924578).
- Kim, G.H., Jeon, S., Im, K., Kwon, H., Lee, B.H., Kim, G.Y., Jeong, H., Han, N.E., Seo, S.W., Cho, H., Noh, Y., Park, S.E., Hojeong, K., Hwang, J.W., Yoon, C.W., Kim, H.J., Byoung, S.Y., Chin, J.H., Kim, J-H., ... Na, D.L. (2015). Structural brain changes after traditional and robot-assisted multi-domain cognitive training in community-dwelling healthy elderly. *PLoS One*, 10(4), Article e0123251.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.
- Kong, A. P.-H. (2020). The use of free non-dementia-specific apps on iPad to conduct group communication exercises for individuals with Alzheimer's disease (innovative practice). *Dementia*, 19(4), 1252-1264.

- Korchut, A., Szklener, S., Abdelnour, C., Tantinya, N., Hernández-Farigola, J., Ribes, J. C., Skrobas, U., Grabowska-Aleksandrowicz, K., Szczeńśniak-Stańczyk, D., & Rejdak, K. (2017). Challenges for service robots-requirements of elderly adults with cognitive impairments. *Frontiers in Neurology*, 8, 228. DOI: [10.3389/fneur.2017.00228](https://doi.org/10.3389/fneur.2017.00228).
- Lee, J.Y.Y., Crooks, R.E., Pham, T., Korngut, L., Patten, S., Jetté, N., Smith, E.E., & Roach, P. (2019). "If it helps someone, then I want to do it": Perspectives of persons living with dementia on research registry participation. *Dementia: The International Journal of Social Research and Practice*. DOI: [10.1177/1471301219827709](https://doi.org/10.1177/1471301219827709).
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.
- Luo, Y., Hawkey L. C., Waite L. J., & Cacioppo J. T. (2012). Loneliness, health, and mortality in old age: A national longitudinal study. *Social Science & Medicine*, 74, 907-914.
- Moyle, W., Kellett, U., Ballantyne, A., & Gracia, N. (2011). Dementia and loneliness: An Australian perspective. *Journal of Clinical Nursing*, 20, 1445-1453.
- Phinney, A. (2006). Family strategies for supporting involvement in meaningful activity by persons with dementia. *Journal of Family Nursing*, 12, 80-101.
- Phinney, A., Chaudhury, H., & O'connor, D. L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging & Mental Health*, 11, 384-393.
- QSR International Pty Ltd. (2018). NVivo qualitative data analysis software, version 12.
- Qualtrics. (2019). Qualtrics, Provo, UT, USA. <https://www.qualtrics.com>
- Roach, P., & Drummond, N. (2014). 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing*, 21, 889-895.
- Roach, P., Drummond, N., & Keady, J. (2016). 'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies*, 36, 26-32.
- Sheikh, F., Ismail, Z., Mortby, M. E., Barber, P., Cieslak, A., Fischer, K., Granger, R., Hogan, D. B., Mackie, A., Maxwell, C. J., Menon, B., Mueller, P., Patry, D., Pearson, D., Quickfall, J., Sajobi, T., Tse, E., Wang, M., Smith, E. E., & for the PROMPT registry investigators. (2018). Prevalence of mild behavioral impairment in mild cognitive impairment and subjective cognitive decline, and its association with caregiver burden. *International Psychogeriatrics*, 30, 233-244. DOI: [10.1017/S104161021700151X](https://doi.org/10.1017/S104161021700151X).
- Sörenson, S., & Conwell, Y. (2011). Issues in dementia caregiving: Effects on mental and physical health, intervention strategies, and research needs. *American Journal of Geriatric Psychiatry*, 19(6), 491-496.
- Street, R. L., Jr., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74, 295-301.
- Takai, M., Takahashi, M., Iwamitsu, Y., Ando, N., Okazaki, S., Nakajima, K., Oishi, S., & Miyaoka, H. (2009). The experience of burnout among home caregivers of patients with dementia: Relations to depression and quality of life. *Archives of Gerontology and Geriatrics*, 49(1), e1-e5.
- Tilvis, R. S., Routasalo, P., Karppinen, H., Strandberg, T. E., Kautiainen, H., & Pitkala, K. H. (2012). Social isolation, social activity and loneliness as survival indicators in old age; A nationwide survey with a 7-year follow-up. *European Geriatric Medicine*, 3, 18-22.
- Vernooij-Dassen, M., & Jeon, Y.-H. (2016). Social health and dementia: The power of human capabilities. *International Psychogeriatrics*, 28(5), 701-703.
- Wang, H., Li, T., Barbarino, P., Gauthier, S., Brodaty, H., Molinuevo, J. L., Xie, H., Sun, Y., Yu, E., Tang, Y., Weidner, W., & Yu, X. (2020). Dementia care during COVID-19. *The Lancet*, 395, 1190-1191.
- Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., Rummery, K., & Keady, J. (2018). The lived neighborhood: Understanding how people with dementia engage with their local environment. *International Psychogeriatrics*, 30(6), 867-880.

Pamela Roach is the Program Manager for the Brain and Mental Health Research Clinics, Hotchkiss Brain Institute; and an Adjunct Assistant Professor, Community Health Sciences at the University of Calgary. She works with people living with dementia to understand experience and improve health services.

Angela Zwiers has a BSc in Health Sciences and MSc in Health and Rehabilitation Sciences from Western University. She is currently a research coordinator working on observational and clinical trials involving Alzheimer's, cerebral amyloid apathy, and other types of dementia.

Emily Cox is a research assistant at the Department of Clinical Neurosciences at the University of Calgary. She obtained her Bachelor of Science (Hons.) in Neuroscience from the University of Calgary in 2018.

Karyn Fischer is a Research RN who works in the Healthy Brian Aging Lab and the Cognitive Neurosciences Clinic at the Foothills Medical Centre. She has 18 years of experience as a research nurse and has been working with people living with dementia since 2011. Her background includes clinical trails and observational studies and currently the primary coordinator for the PROMPT registry in the Cognitive Neurosciences Clinic.

Anna Charlton is a clinical research project manager in the Department of Clinical Neurosciences at the University of Calgary. She manages the Clinical Research Laboratory on Vascular Cognitive Impairment and Stroke. Affiliation would be Department of Clinical Neurosciences, University of Calgary.

Colin Josephson is an assistant professor of Neurology and Community Health Sciences at the University of Calgary. He has specialist training in epilepsy and EEG and is director of the Calgary Comprehensive Epilepsy Program Registry. His research interests include "big data," advanced analytics, prediction modeling as a means of better understanding the epidemiology, and clinical outcomes in epilepsy.

Scott Patten obtained a medical doctorate (MD) from the University of Alberta (Edmonton, Canada) in 1986 and subsequently a specialist certification (FRCPC) in Psychiatry in 1991. He completed a PhD in epidemiology at the University of Calgary in 1994. Currently, he is a professor in the Cumming School of Medicine at the University of Calgary, where he holds the Cuthbertson and Fischer Chair in Pediatric Mental Health.

Dallas Seitz is an associate professor in the Department of Psychiatry and Community Health Sciences in the Cumming School of Medicine, University of Calgary and the current President of the Canadian Academy of Geriatric Psychiatry. His research examines health service utilization of older adults with psychiatric disorders, evaluation of the safety and efficacy of treatments for geriatric mental health conditions, and knowledge translation in geriatric mental health.

Zahinoor Ismail is an associate professor of Psychiatry, Neurology, and Epidemiology at the Hotchkiss Brain Institute and O'Brien Institute for Public Health at the University of Calgary. His research focuses on early dementia detection and assessment and management of neuropsychiatric symptoms in dementia and pre-dementia patients.

Eric Smith is the Medical Director of the Cognitive Neurosciences Clinic, Professor of Neurology in the Department of Clinical Neurosciences at the University of Calgary, and holder of the Kathy Taylor Chair in Vascular Dementia at the University of Calgary.