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Examining the Needs of Family Caregivers of People Living with Dementia in the Community during the COVID-19 Pandemic

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Article

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Résumé

La pandémie de COVID-19 a eu un effet disproportionné sur les personnes âgées et leurs proches aidants. Pour les proches aidants, la pandémie a eu des répercussions sur presque toutes les dimensions de leur vie et de leurs routines de prestation de soins, depuis leur propre risque de tomber malade jusqu'à l'accès à des ressources de soutien. Cette étude hybride avait pour but d'examiner l'impact de la COVID-19 sur la capacité des proches aidants de fournir des soins au membre de leur famille atteint de démence. Un total de 115 proches aidants qui ont déclaré avoir un membre de leur famille qui vit avec la démence et réside dans la communauté ont participé au sondage. Dix proches aidants ont participé aux groupes de discussion qui ont suivi. Les recommandations pour répondre aux besoins des proches aidants aujourd'hui et à l'avenir comprennent les suivantes : (1) Les ressources de soutien à la prestation de soins doivent être constamment accessibles et adaptées, (2) Les proches aidants ont besoin de soutien pour s'orienter dans le système de santé, et (3) Une information concise est nécessaire sur la marche à suivre pour fournir des soins en périodes d'urgences de santé publique.

Abstract

The COVID-19 pandemic has had a disproportionate effect on older adults and their family caregivers (FCGs). For FCGs, the pandemic has impacted almost every dimension of their lives and caregiving routines, from their own risk of becoming ill to their access to resources that support caregiving. The purpose of this mixed-methods study was to examine the impact of COVID-19 on FCGs' ability to provide care for their family member with dementia. A total of 115 FCGs who identified as having their family member living with dementia residing in the community completed the survey. Ten family caregivers participated in the follow-up focus groups. Recommendations to address the needs of FCGs now and in the future include: (1) making resources for care provision consistently available and tailored, (2) providing support for navigating the health care system, and (3) supplying concise information on how to provide care during public health emergencies.

Introduction

The COVID-19 pandemic has had a disproportionate effect on older adults with chronic conditions, such as dementia, and their family caregivers (FCGs) (Meisner et al., 2020). For FCGs, the pandemic has impacted almost every dimension of their lives and caregiving routines, from their own risk of becoming ill to their access to resources that support caregiving. Even before COVID-19, FCGs were a critical factor enabling people living with dementia to remain in the community, often being noted as "a critical national health care resource" (Schulz & Sherwood, 2008). In Canada, there are 8,100,000 FCGs, comprising 28 per cent of the population and contributing $25 billion annually in unpaid care (Family Caregiver Alliance, 2019; Sinha, 2013). An FCG is an unpaid individual (e.g., a spouse, partner, family member, friend, or neighbor) who is involved in assisting with activities of daily living and/or everyday tasks. Care provision is a complex and variable activity requiring multidimensional support that extends across physical, psychological, spiritual, and emotional domains (Honea et al., 2008). Despite the complexity of the role and potential negative outcomes, FCGs are often providing care without adequate or affordable resources and support services (Schulz, Beach, Czaja, Martire, & Monin, 2020). Typically, FCGs are responsible for providing both emotional and physical care as well as for organizing and coordinating health services on behalf of their family member, including those with dementia (Stajduhar, Martin, Barwich, & Fyles, 2008).

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Dementia is a common chronic health condition among older adults, impacting 7.1 per cent of Canadians over the age of 65 (Public Health Agency of Canada, 2017). Dementia is characterized by progressive cognitive impairment that interferes with daily life (Boscart, McNeill, & Grinspun, 2019), resulting in the person living with dementia becoming increasingly reliant on their FCGs. As the disease progresses, people living with dementia become more dependent on their FCG to assist with even the basic activities of daily living, which increases the stress of caregiving and negatively affects the health of the FCG, further reducing their ability to support their family member with dementia (Kolanowski et al., 2017; Livingston et al., 2020). FCGs often operate at the limits of their abilities, juggling the pressures and commitments of their own lives, family, and work while also providing increasing amounts of care (Sinha, 2013).

Over the last several months, FCGs have faced additional care-associated challenges because of the COVID-19 pandemic. The memory impairment associated with dementia makes protective measures such as social distancing, wearing masks, and hand washing more difficult, resulting in people living with dementia being more susceptible to COVID-19 infection. If people living with dementia require hospitalization (for COVID-19 infection or other related illnesses), they experience extra stress caused by being the unfamiliar surroundings, which is further complicated by hypoxia-induced delirium, a common COVID-19 symptom, increasing patient suffering and cost of care (Boltz, 2012; Lopez, Mazor, Mitchell, & Givens, 2013; Molony, Kolanowski, Van Haitsma, & Rooney, 2018; Wang et al., 2020).

FCGs are key partners in the health care system, as they provide 70–80 per cent of the care for people living with dementia in the community (Sinha, 2013). Although the caregiving role has many positive aspects, the negative impacts the role has on FCGs' physical and mental health, social relationships, employment, and financial well-being are well documented (Beam et al., 2018; Carers UK, 2020; Chambers, Bancej, & McDowell, 2016; Health Council of Canada, 2012; Kolanowski et al., 2017; Toot, Swinson, Devine, Challis, & Orrell, 2017). These negative outcomes for FCGs have only been exacerbated by the current COVID-19 pandemic.

To mitigate the serious and often fatal effects of COVID-19 on older adults, Provincial Health Ministries across Canada enacted numerous public health measures that eliminated or reduced support services and resources for FCGs providing care for people living with dementia, including those living in the community. Since COVID-19 began, FCGs have reported increased stress, greater difficulty caring for their family member, and a general decline in their family member with dementia (Cohen, Russo, Campos, & Allegri, 2020). Although there has been considerable media attention directed at the experiences of older adults in assisted/supportive living and long-term care, much less attention has been directed at understanding the effects of the public health measures on FCGs and people living with dementia residing in the community. Further, the rapidly changing public health messaging and public health measures have left many FCGs confused about how to access resources and support for their own care, as well as caring for the person living with dementia.

As older adults have confronted the realities of living through the COVID-19 pandemic, FCGs have fulfilled an ever-expanding role in helping to curb the spread of the disease, as well as helping their family member with dementia cope with the stress and anxiety of this unprecedented situation. The health care system has also increasingly relied on FCGs. Many FCGs report providing an average of 10 additional hours of care per week, while at the same time providing higher levels of care as a result of local resources and supports being reduced or closed (Carers UK, 2020). These increased responsibilities coupled with the evolving directions of Health Ministries as they have confronted and responded to an ever changing COVID-19 pandemic add to the complexity of the FCGs' provision of care.

To better support FCGs during the current COVID-19 pandemic and prepare for future public health emergencies, a greater understanding of the effects of COVID-19 on the caregiving experience and the systemic gaps in essential care provision resources for the caregiving dyad (the FCG and the person living with dementia) is critically needed. Unfortunately, little is known about how to provide resources during a pandemic in a way that both promotes public health and enables FCGs to continue providing care. As such, the purpose of this study was to examine the impact of the COVID-19 pandemic on FCGs' ability to provide care for their family member with dementia and the effect of pandemic-related public health measures on the outcomes of the caregiving dyad.

Methods

Design

To examine the impact of the COVID-19 pandemic on FCGs for people living with dementia, a mixed-methods approach was employed along with community-based research strategies. A community advisory committee (CAC) with members from our partner organizations, the Alzheimer Society of Calgary and Dementia Network Calgary, as well as with members from our study participant population (FCGs) was formed. The CAC guided the study design, survey questions, and focus group guidelines, and aided with the interpretation and validation of the study findings.

To obtain complementary data, the quantitative and qualitative data were collected sequentially. The results of the two analyses were compared and contrasted leading to an overall interpretation of the findings (Martínez-Mesa, González-Chica, Duquia, Bonamigo, & Bastos, 2016). The quantitative survey portion of the study informed the qualitative data collected from focus groups with FCGs. Data were collected in the late spring (quantitative) and early summer (qualitative) of 2020, just after the peak of the first wave in the province in which the study was conducted. Full public health measures were still enacted during the study time frame.

The theoretical framework underpinning the study is Hobfoll's Conservation of Resources (COR) Model (Halbesleben, Neveu, Paustian-Underdahl, & Westman, 2014; Hobfoll, 1989, 1998, 2001; Hobfoll, Halbesleben, Neveu, & Westman, 2018; Hong & Harrington, 2016). COR is an integrated stress theory, which places equal emphasis on the environmental and internal aspects of the stress process (Hobfoll, 1989). In this model, the focus is on the resources that preserve well-being in the face of stressful situations (Hobfoll, 2001). Using COR allows for the examination of how the changing environmental factors during a public health emergency, such as COVID-19, affect the resources available to FCGs. It also provides a foundation for understanding outcomes for the caregiving dyad by considering their contextual and environmental situations.

Ethical approval for the study was obtained from the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary (REB20-0855).

Sampling, Data Collection, and Analysis

Informed consent was obtained from all study participants. Participant eligibility included being over the age of 18 and providing care for a person living with dementia during the COVID-19 pandemic, and the ability to read and write in English. An online survey was conducted in June and July of 2020. A link to the survey was distributed through our community partners using electronic newsletters, organization Web pages, and social media pages. Focus group participants were recruited from the survey participants, with a question prompting participants to provide their e-mail address if they were willing to participate in focus group follow-up.

The survey instrument platform utilized for the survey delivery was Qualtrics. The data collected were analyzed quantitatively using IBM Statistical Package for Social Sciences software (IBM SPSS) version 26 using descriptive and correlation statistics, and multiple regression models.

Focus groups were conducted online using videoconferencing and teleconferencing software and were led by members of the research team who are experts in focus group facilitation. Focus groups lasted 60–90 minutes and were recorded. The recordings were then transcribed verbatim by an expert in transcription. NVivo data analysis software was used for qualitative data management. Using thematic analysis, the focus group transcripts were iteratively examined by two team members to identify concepts and compare for similarities and differences (Braun & Clarke, 2006; Nowell, Norris, White, & Moules, 2017). Constantly moving back and forth within the data set allowed for the identification of initial codes. In the next phase, codes that were conceptually similar were grouped to search for themes within the data and were then organized hierarchically. The process was repeated until no new themes were identified, at which point the themes were refined and named (Braun & Clarke, 2006). Prolonged engagement with the data and monthly debriefing meetings with our CAC contributed to the credibility, dependability, and confirmability of the analysis (Nowell et al., 2017). The consolidated criteria for reporting qualitative research (COREQ) checklist was used as a guide for analyzing and interpreting the focus group results (Tong, Sainsbury, & Craig, 2007). See Appendix for a list of the focus group guiding questions.

Measures

Survey questions were adapted from published scales that collect data regarding caregiving routine, caregiver burden, strain, and quality of life, as well as observed changes in behaviour and activities for people living with dementia. In addition to the scales, three open-ended questions were asked: (1) What did you miss the most as a caregiver during the COVID-19 pandemic? (2) What was your biggest worry as a caregiver during the COVID-19 pandemic? and (3) What positive caregiving experiences did you have as a result of the COVID-19 pandemic?

All scales were adapted specifically for this study with the guidance of our CAC. The scales are as follows.

Change in caregiving hours

A single-item question was used to assess self-rated change in caregiving hours. Measured on a three-point Likert scale (1=less time, 2=about the same, 3=more time caregiving), higher scores indicate a greater amount of time spent caregiving while lower scores indicate less time spent caregiving.

Caregiving routine

We adapted our survey questions from Irani, Niyomyart, and Hickman's (2021) Family Caregiving During the U.S. COVID-19 Pandemic questionnaire, which asks whether or not specific caregiving activities have changed during the pandemic. The original survey responses were scored on a scale (less than, same, more than). We adapted the scale responses as Yes/No with the option to not select a response if not applicable. Each "Yes" was scored as 1 and summed to provide a total score for caregiving change. Higher scores equal a greater change in the caregiving routine. A sample adapted question is "Has the pandemic affected your caregiving routine?

Caregiver burden

Adapted from the Zarit Caregiver Burden Scale (Zarit, Reever, & Bach-Peterson, 1980), the questions evaluate the level of burden being experienced by the caregiver. The original scale used the word "relative" in the burden statements; we adapted that to be "person with dementia". Measured on a five-point Likert (0 = strongly disagree, 4 = strongly agree), higher scores indicate higher feelings of caregiving burden. A sample adapted question is "I feel angry when I am around the person with dementia."

Caregiver strain

A single item question was used to assess self-rated caregiving strain. Measured on a three-point Likert scale (1=less than usual, 2=about the same, 3=more than usual), higher scores indicate higher self-rated feelings of caregiving strain.

Quality of life (caregiver)

A single-item question was used to assess self-rated quality of life during the pandemic. Measured on a three-point Likert scale (1=less than usual, 2=about the same, 3=more than usual), higher scores indicate higher self-rated quality of life.

Change in everyday activities (for the person living with dementia)

Adapted from the Bristol Activities of Daily Living Scale (Bucks, Ashworth, Wilcock, & Siegfried, 1996), the questions evaluate the FCG's perception of the change in the everyday activities they complete for the person living with dementia. The original scale was listed for each question with options a through e to referring to a different level of ability. We adapted the scale to a four-point Likert scale (0 = I don't usually do this, 1=less than usual, 2=about the same, 3=more than usual). Higher scores indicate increased or a higher level of assistance with everyday activities of daily living for the person living with dementia. A sample adapted question is "During the pandemic, I am helping the person with dementia with getting dressed."

Responsive behaviours (of the person living with dementia)

Adapted from the Neuropsychiatric Inventory Questionnaire (Cummings, 1994), the questions evaluate the FCG's perception of changes in the neuropsychiatric behaviours of the person living with dementia. The original scale used the word "patient" in the behaviour statements, we adapted that to "person with dementia".

Responses were adapted from severity measures to frequency measures. (Measured on a three-point Likert scale (1=decreased, 2=remained the same, 3=increased, 0=not applicable), higher scores indicate increased or higher levels of responsive behaviour for the person living with dementia. A sample adapted question is "During the pandemic, the following behaviour (e.g. delusions) of the person with dementia I care for has…".

Control variables

Seven control variables were included in the data analyses; five individual variables for the FCG and two variables for the person living with dementia for whom they provide care. The FCG variables include: (1) gender, (2) age, (3) education level, (4) length of time as a caregiver, and (5) relationship to the person living with dementia. The variables for the person living with dementia include: (1) gender and (2) age.

Results

Quantitative Analysis

A total of 115 FCGs who identified as having their family member living with dementia residing in the community completed the survey. The majority of the respondents are female caregivers (74.6%), have a university degree (37.7%), and are 71–80 years of age (32.5%). The majority of the people living with dementia whom they care for are women (50.9%), 71–80 years of age or older (41.2% and 38.6% respectively), and either a spouse/partner (66.1%) or the parent of the caregiver (24.3%). Twenty-two people with dementia live on their own, while 93 live in the community with their FCG (80.9%). As the study was conducted at the beginning of COVID-19, in spring 2020, FCGs reporting less than 1 year of caregiving (12%) would have started providing care to their family member living with dementia approximately when the pandemic emerged in Canada. See Table 1 for participant demographics.

From the quantitative data we found that: (1) 58.3 per cent of FCGs had a significant increase in the number of hours providing care, (2) 67.8 per cent are feeling more strain, and (3) 60.2 per cent reported a decrease in their quality of life during COVID-19 compared to pre-pandemic. Resources and supports were a concern, as FCGs went from using an average of five resources pre COVID-19 to using 1.7 resources during the pandemic. Among the highest drop in resource use included: transportation services (100%), day programs (97%), legal planning (83%), end-of-life planning (82.5%), and support groups (72.5%). See Table 2 for descriptive statistics and Table 3 for caregiving resources used before and during the COVID-19 pandemic.

We expected that the pandemic and associated public health restrictions would result in an increase in the caregiving role for FCGs and would lead to less than optimal outcomes for the both the FCG and the person living with dementia. As shown in Table 4, multiple regression analysis showed that increases in caregiving hours resulted in poorer outcomes for both the FCG and the person living with dementia. In the first regression model, an increase in caregiving hours was found to be significantly related to higher levels of FCG self-reported burden (ß = 0.354, $p < 0.001$). In the second regression model, an increase in caregiving hours was found to be significantly related to higher levels of FCG self-reported strain (ß = 0.255, $p < 0.05$). In the third regression model, an increase in caregiving hours was found to be significantly related to lower levels of FCG self-reported quality of life (ß = -0.178, $p < 0.10$). Increased caregiving hours in the fourth model were significantly related to higher levels of FCG perceptions of their need to complete activities of daily life for the person living with dementia (ß = 0.419, $p < 0.001$). Finally, the fifth model found that an increase in caregiving hours was significantly related to higher levels of FCG perceptions of an increase in responsive behaviours for their family member with dementia (ß = 0.173, $p < 0.10$). These findings offer support for the study expectations that pandemic and associated public health restrictions would result in an expanded role for FCGs and have a negative impact on them and their family member with dementia.

Table 1. Participant demographics

	n	%
Gender		
Female	85	74.6
Male	29	25.4
Age		
≤ 50 years	12	10.5
51–60 years	19	16.7
61–70 years	36	31.6
71–80 years	37	32.5
> 80 years	10	8.8
Education		
High school diploma/equivalent or less	14	12.3
Community/Technical college	33	28.9
University	43	37.7
Graduate degree	23	20.2
How long caregiving		
< 1 year	14	12.2
1–2 years	20	17.4
2–4 years	33	28.7
> 4 years	48	41.7
Relationship to person living with dementia		
Spouse/partner	76	66.1
Child/child-in-law	28	24.3
Other relative	9	7.8
Neighbor/friend	2	1.7
Person living with dementia - gender		
Female	58	50.9
Male	56	49.1
Person living with dementia - age		
51–60 years	3	2.6
61–70 years	20	17.5
71–80 years	47	41.2
> 80 years	44	38.6

Note. $n = 115$. Columns may not total exactly because of rounding and/or missing information.

Table 2. Descriptive statistics and correlations

Variable	M	SD	1	2	3	4	5	6	7
1. Change in caregiving hours	2.52	0.61	1.0						
2. Change in caregiving routine	3.0	1.62	0.29**	1.0					
3. FCG burden	27.74	10.09	0.346**	0.078	1.0				
4. FCG strain	2.68	0.47	0.254**	0.069	0.382**	1.0			
5. FCG quality of Life	1.44	0.58	–0.189*	–0.089	0.388**	–0.281**	1.0		
6. PLWD ADLs	2.27	0.33	0.419**	0.099	0.225*	0.366**	–0.168	1.0	
7. PLWD responsive behav.	2.40	0.33	0.212*	0.182	0.233*	0.464**	–0.026	0.305**	1.0

Note. $n = 115$. **$p < .01$, *$p < .05$
FCG = family caregiver; PLWD = person living with dementia; ADLs = activities of daily living.

Table 3. Changes in resource access/services

Resource	Number Using Before COVID	Number Using During COVID	Percentage Decline
Transportation services	21	0	100%
Day programs	33	1	96.96%
Legal planning	42	7	83.33%
End-of-life planning	40	7	82.5%
Support groups	40	11	72.5%
Home nursing visits	28	8	69.23%
Day respite	28	9	67.85%
Accessing CG information	61	23	62.29%
Financial planning	50	19	62.0%
Home care assistance	33	134	60.6%

Note. Sample size = 115

Open-Ended Survey Questions Findings

The survey also included open-ended questions, in which FCGs were asked about what they were missing most and their biggest worries during the COVID-19 pandemic. FCGs in the community indicated that an increase in social isolation and a lack of respite and supportive resources were negatively affecting their quality of life and ability to provide care. They worried about adequate care for the person living with dementia and how to maintain both their own health and their family member's health during the pandemic. This worry was related to their family member possibly contracting COVID-19, as well as about the progression of dementia as a result of the increased social isolation. There was also concern over who would care for their family member should they themselves become ill; as one participant stated: "If I get sick, what then?" When asked about what they were missing most, FCGs described the lack of face-to-face contact as well as engagement with the "outside world" for both themselves and their family member with dementia. FCGs indicated that not having access to essential health and social support services, such as respite, adult day programs, and home care as well as their support networks contributed to their caregiving burden during COVID-19. When asked if there were any positive aspects of providing care during COVID-19, FCGs reported having closer relationships with friends and family. Additionally, the FCGs expressed gratitude for the support they had received as well as for the health care professionals who continued to provide care despite the challenges posed by COVID-19.

Qualitative Analysis

The survey data informed the follow-up focus groups that were conducted with FCGs from the community. Three focus groups were conducted with a total of 10 family caregivers. All of the focus group participants were female and Caucasian, with 60 per cent having completed an undergraduate or graduate degree. The average age of the FCG participant was 63 years, with 50 per cent of participants caring for a parent or parent-in-law, and 40 per cent caring for a spouse or partner. The majority of participants (80%) spent more than 10 hours per week providing care. From the focus groups with FCGs, the three overarching themes are: (1) reduced resources resulting from COVID-19 public health measures,

Table 4. Regression models: Changes in caregiving on outcomes for FCGs and PLWD

	Dependent Variables				
	Burden	Strain	Qual Life	ADLs	Respon. Behav.
	Std ß	Std ß	Std ß	Std ß	Std ß
Independent variables					
Change in hours caregiving (increase)	0.354***	0.255**	–0.178*	0.419***	0.173*
Change in caregiving routine	–0.025	–0.005	–0.037	0.002	0.132
R^2	0.120	0.064	0.037	0.176	0.061
F Value	7.67**	3.85**	2.11	11.40***	3.597**
Sample size	114	114	112	109	113

Note. ADLs = activities of daily living; Std ß = Standardized beta coefficient.
***$p < 0.001$, **$p < 0.05$, *$p < 0.10$.

(2) navigating the health care system, and (3) caregiving adaptations made during COVID-19.

Reduced resources resulting from COVID-19 public health measures

The first theme from the focus groups was *reduced resources resulting from COVID-19 public health measures.*

As in the survey, FCGs continued to express concern about the decrease or even absence of needed resources, including adult day programs, home care, and respite, and the resulting unmet needs. One of the unintended consequences of the public health measures put in place to address the spread of COVID-19 was increased social isolation. Resources and supports that were available pre-COVID-19 were decreased or cancelled. During the focus groups, FCGs discussed how COVID-19 changed access to resources that were previously available:

> We had help with housework, helping with meal preps, that kind of thing. It all just stopped when COVID happened partly out of fear on my parents' side of having people coming in [pause] and they would have liked to have had some help but there was nothing, nothing left to help them.

Caregivers at home and in the community noted that the closing of adult day programs as lockdowns began was a significant loss for themselves and their family member. Losing the adult day program removed a source of respite for the FCGs and a social venue for the person living with dementia. As one FCG stated:

> My husband was going to [day program] but that was cancelled, fingers crossed that it is going to start up again but they reduced the numbers that they're going to [accept] because of COVID. So for him he lost that one day a week where he could interact with other people and the support groups that I belong to of course were cancelled.

Home care services were also cut back and rearranged significantly, leading to greater strain on caregivers. One FCG shared:

> When things started happening we basically kept my mother at home, her support group was cancelled and then we heard the seniors care that they had cancelled the lady who came to help her everyday or every couple of days with her shower. [Inaudible] and she (had) been part of a seniors support group over at [care home]. All of this stopped and then I got a phone call from seniors care asking if we'd be willing to take over the care of mom because they were trying to minimize the amount of contact that she had with other people, and so we kind of went ok fine we'll take it on ourselves, so everything that we had in place stopped, just stopped.

In addition to home care, access to private paid care was also impacted by public health measures, and FCGs wanting to keep their family member with dementia safe as reflected in the following FCG comment:

> I am the primary caregiver and I do get tired; because I am facing this knee replacement my ability has been affected. Up until the lockdown we had a helper, we hired somebody privately to help me with light housework and to be in the house so I could go out, so I could go shopping, run errands, appointments, meet a friend occasionally. But as soon the outbreak, the lockdown happened I cancelled her because she works part time at a long term care home, and she also has a family at home, and her older parents at home too, so she wanted also to protect her family.

As resources and supports were reduced, FCGs stressed the need for respite care, which was also unavailable to them as highlighted by the following: "you know it's a hard struggle all by yourself [pause] I want to run away and not do anything anymore, 'cause I'm not young anymore either, I want to just to have some time to myself but I haven't had that." Another FCG referred to the lack of respite as follows:

> There needs to be respite for the people that are not in care facilities, like we need that too 'cause yeah, you hear about the fallout of mental health in the midst of this pandemic and it's a very real thing that we're dealing with here right now, and it just compounds everything.

There was also uncertainty about the future and about knowing how potential changes to public health measures could impact their access to resources, including home care and respite, with one FCG sharing "What are the protocols going to be for our respite people, for our people coming to visit, are they going to be in our homes and if so, what are the restrictions, what do we have to do?"

Navigation of the health care system

The second theme from the focus groups was *navigation of the health care system.* FCGs stressed that they need ongoing access to professional support, including access to medical professionals, specialists, and case workers or social workers to assist with system navigation. FCGs reported having to pay particular attention to managing the co-morbid conditions of the person living with dementia, which included high blood pressure, chronic obstructive pulmonary disease (COPD), heart conditions, diabetes, arthritis, and mobility issues. Managing these health conditions sometimes became more complex for FCGs during the pandemic, as availability of appointments with specialists was reduced.

FCGs noted that many specialist services were closed down or delayed indefinitely, resulting in delayed surgical procedures, physiotherapy treatments, mental health assessments, and routine checkups. For FCGs with less than 1 year of caregiving experience, postponements delayed dementia diagnosis and treatment, thus delaying their being connected with needed resources and supports. As new dementia diagnoses continued during the pandemic, FCGs were often expected to cope with this new information with fewer resources, less time with physicians, and fewer in-person visits as highlighted by:

> Because of COVID [family member] was supposed to see a geriatric psychiatrist, and you know her family doctor, all these medical people, everything got delayed for months because of the lockdown, cause no one's offices were open, they weren't seeing patients for assessments and stuff right, so she didn't get to see the geriatric psychiatrist until the end of May, the end of May so that delayed us getting sort of an assessment saying yes this what I think she has, they put her on some drugs, you know so we struggled with her family doctor from January onward about isn't there anything you can do to help her with this anxiety and this dementia, cause at that point we thought maybe there was some kind of help that she could get. We had to wait so long to get medical attention during the COVID because doctors just weren't working, their offices were shut down.

One area that FCGs stressed was how disruptive and challenging navigating a new diagnosis during the pandemic had been, and the critical need for ongoing information about dementia and support surrounding the diagnosis:

> Nobody has ever sat and talked with me about what I can expect [pause] I didn't know any of it, and it's all been just learning by the seat of my pants basically. If somebody would have had the time to spend with us to help me figure out what's going to take place that would have been extremely helpful.

Navigating the available resources and supports also became more complex during COVID-19, and participants reported feeling abandoned by the system, as one FCG explained: "the worst part of the whole thing is not knowing how to navigate the system, and not feeling supported by anyone."

As the resource landscape and restrictions shifted, even FCGs who had been connected to case workers or navigation services felt that they were often left to fall through the gaps: "Mom's case manager left for three weeks or so and nobody took over her case, so everything was on hold for three weeks 'till she got back, nobody would move ahead with anything that I needed or wanted." During care transitions, especially in the context of the pandemic, FCGs felt particularly lost and without support. As a result of these transitions, FCGs may no longer have qualified for their previous services, while at the same time the new facilities (hospitals, supportive living, long-term care) were unable to address these gaps in care. As one FCG elaborated:

> We lost continuity with each phase that she went through in terms of who we were talking to, who understands the reality of what we were facing [pause] it feels like as soon as she went into hospital, and she became the hospital's problem, we didn't hear from her [dementia care] team anymore. As soon as the hospital determined that she needed to go into transition services for long-term care, it became the transition services at the hospital. So I felt like I was filling in a lot of gaps that I ultimately would have liked another department [to do].

Caregiving adaptations made during COVID-19

The third theme, *caregiving adaptations made during COVID-19*, highlights the need for adaptations of available resources and services to meet evolving needs during the pandemic. For FCGs in the community setting there was a loss of connection with the outside world as well as loss of critical supports that were available pre-COVID-19. FCGs discussed the need to be creative in adapting their caregiving routines to address the limitations imposed by the pandemic.

One adaptation was adjusting to the perceived lack of information regarding the resources that were still available and how to access them, with one FCG stating:

> What resources are available, well I don't know…so maybe that would be a good thing to give a list, you know what is there today because a lot of times there might be resources but no one knows to ask for something when they don't even know what it is.

Many caregivers pointed out that little to no information had been made available to them about supports available and ways to adapt their caregiving during COVID-19:

> I would say that there really hasn't been any information about caregiving during COVID, and so I think that would probably fall into the bucket of I don't know what I don't know, there could be different things that would have been more helpful.

One FCG suggested including information in a magazine:

> What about magazines, like when I went to physio I picked this up which, it was just helpful to know what was going on, and we've always had to pick it up wherever it was available at the church, the church is closed, but if some of those things could be mailed it would be really helpful to have that little look at what's happening in the outside world.

Other adaptations for gaining information included attending webinars and online workshops as reflected in the following:

> I also did a workshop very recently on caregiving strategies, and that helped a lot because it helped me realize that I'm not at burnout, you know it analyzed stress, it analyzed accumulated stress, and it really helped put things in perspective.

Caregivers suggested non-traditional formats for outdoor visits, and extra precautions that would allow respite care to continue and allow them some time away. They suggested creative thinking around how to offer day programs and options for social connectivity during a pandemic:

> We know that resources are stretched in order to deal with the pandemic but if there is any way, because dementia is so invasive on caregivers' lives and futures but if there could be some sort of safe place where the loved ones could go. At least a welcome center or a community place, even once a week, even for a couple of hours, could they develop that where the staff obviously are fully protected but so are the loved ones, so there still is that opportunity and awareness that these people need to come out of the home or that the caregivers still need a break!

To facilitate the need for physical distance during the pandemic, technology was used to provide support to FCGs. For example, videoconferencing was used to provide a space for virtual groups that some found very beneficial:

> I also found that all of these video conferences and Zoom were fantastic. I, found a very special exercise class to help strengthen my legs and to deal with the osteoarthritis pain, and that was all done by Zoom, and that was fantastic because twice a week I could forget being the caregiver of a person with dementia, and meet these other people and have a good exercise class and help myself, so technology helped a lot, it really did, I don't think I would have survived without technology.

Many adult day programs pivoted from face-to-face to an online format, which facilitated the engagement of the people living with dementia, as one FCG shared: "I will say [adult day program] has been doing Zoom with us [pause] so they do music and they do trivia, they do exercise every afternoon for an hour and that has been a real help."

Although technology was beneficial for some, it was unfortunately a barrier to accessing available resources for other FCGs. Some of the FCGs discussed how participating in support groups via videoconferencing was not an option for them as it was upsetting to the person living with dementia: "…the one support group I was in did have five weekly Zoom calls but it wasn't something I was able to do because my husband would always feel like I was talking about him, and he would object." Others did not feel comfortable with the technology and this was also a barrier to access: "I'm embarrassed to say that I don't have Zoom, I just have a desktop computer and can't figure out how to find sound on it, and I don't have a camera."

Discussion

In 2002, Roy Romanow, of the Royal Commission, acknowledged that the Canadian health system was unsustainable without the work of FCGs: "With more and more Canadians being treated at home rather than in other care centres, the burden on informal caregivers has grown significantly. Our health care system simply could not function without the thousands of parents, loved ones, family and friends that provide direct support…" (Romanow, 2002). Since that report, there have been numerous publications emphasizing the Royal Commission's message, yet the burden on FCGs continues to increase, and has only been exacerbated by the COVID-19 pandemic. The exacerbation of FCG burden was demonstrated in our study with the participants reporting increased hours of providing care because they did not have access to essential health and social support services as well as not having access to their social support networks. COVID-19-related policies have greatly impacted FCGs' ability to maintain their usual care provision as a result of reduced access to caregiving support resources and restrictions on routine daily life (Chu, Donato-Woodger, & Dainton, 2020; Hoffman, Webster, & Bynum, 2020), despite FCGs being essential care partners for people living with dementia. The decrease in the number of resources or decreased access as a result of the public health restrictions affected the FGCs' ability to provide care for their family member with dementia as well as affecting their own quality of life.

Although providing care can be complex and can result in potential negative outcomes, FCGs in our study were often left without adequate or affordable resources and support services, resulting in unmet needs for services and support. These findings align with a study by Black et al. (2013), which found that 97 per cent had one or more unmet needs, with 85 per cent of those having unmet needs for resource referrals or caregiver education (such as available home- and community-based resources). Unmet needs for those in the caregiving role have only been heightened during COVID-19 as a result of the related public health restrictions. The sudden changes to access and loss of health and social support services had a negative impact on the well-being of both the person living with dementia and their FCG (Giebel et al., 2021; Hanna et al., 2022).

System navigation is another critical issue, as FCGs spend 15–50 per cent of their time navigating, negotiating, and managing services within health and social care systems (Buckner & Yeandle, 2015; Schulz et al., 2018; Taylor & Quesnel-Vallée, 2017). As FCGs for people living with dementia spend significant time providing care and navigating a complex health care system (approximately 26 hours/week pre COVID-19 public health measures), approximately 45 per cent experience high levels of distress, including depression and feeling unable to continue providing care (Carers UK, 2020). System navigation was another area that was found to contribute to FCG burden in our study, with FCGs spending an increased amount of time trying to locate applicable resources and supports for the person living with dementia as well as for themselves. FCGs were part of a fragmented health care system pre-COVID-19, and this was only made worse by the restrictions necessitated by the pandemic. Additionally, FCGs are often spouses, themselves older and facing a double jeopardy: while they provide supportive care, they too suffer multiple chronic conditions and health decline (McGhan, Loeb, Baney, & Penrod, 2013; Small, 2016). The double jeopardy that FCGs face when providing care was also exacerbated for them in our study, as was evidenced by their concern about what would happen if they were to become ill and about their increased isolation resulting from trying to keep their family member safe.

COVID-19 has highlighted pre-existing gaps in services and supports for older adults and their FCGs (Hoffman et al., 2020). During COVID-19, FCGs have faced numerous barriers to accessing resources, such as the changing availability of resources or not knowing where to access needed information. FCGs showed great resiliency and adaptability in meeting the challenges posed by COVID-19. In order to meet the needs of their family member with dementia, FCGs made adaptations to their caregiving routine, such as taking on increased responsibilities when home care or respite may have not been available. FCGs also made several suggestions for ways to address the ever-evolving public health measures during COVID-19, such as the use of technology and balancing the risk of infection with the need for social engagement.

Recommendations

To address the issues highlighted by FCGs, the following recommendations for providing support to FCGs during public health emergencies, such as the COVID-19 pandemic include:

1. *Resources for care provision need to be consistently available and tailored to the individual needs of the FCG and person living with dementia to reflect the heterogeneity of the caregiving role.* FCGs in the community emphasized the burden that shuttering respite, home care, and day programs put on them, and expressed a deep need for creative adaptations that would allow these services to continue operating safely during a health emergency. Creative solutions for resources such as adult day programs, need to be offered to maintain social connectivity during a pandemic. Pivoting to virtual environments to address care provision needs may work in some situations but others may require in-person solutions. During the pandemic, virtual or telephone-based support groups were sometimes of limited utility. As with all other resources, support groups should be fostered across diverse models, including text-based message boards or e-mail groups; virtual video or telephone calls; and physically distanced and/or outdoor meetups when safe.
2. *Support in navigating the health care system needs to be provided.* FCGs need access to both general and specific information about a dementia diagnosis, and possible disease trajectories, in order to best support themselves and their family member. To facilitate care provision and access to the supports and resources, FCGs require a single point of contact particularly during times of care transitions. This single point of contact could be a consolidated resource hub that centralizes evidence, resources, training, and best practices that would help family caregivers in their care provision role. An example would be the Alzheimer Society's First Link®, which has a range of services, information, and support programs for people living with dementia and their FCGs.
3. *Accurate and concise information is needed on how to provide care during public health emergencies.* Essential health and social support services, such as home care and respite, need to remain available to facilitate FCGs' being able to continue to provide care in the community. Providing updated information on specific

resources and community services that remained available as well as those that were closed during COVID-19, will help address the barriers to access that were experienced by the FCGs. Information on available supports and ways to adapt care provision during public health emergencies would be particularly helpful, because FCGs may not know how to seek out this information. FCGs highlighted the challenges encountered when improvising care routines in isolation, without knowing whether supports or other options were available.

4. *Recommendations for future research.* Areas for investigation in future studies could include examining the long-term effects of the public health measures on the caregiving experience of the FCGs as well as the impact on their family member living with dementia and if there is a difference in institutionalization rates pre- and post-Covid-19.

Limitations

There are limitations within the study that must be considered when interpreting the results. This was a cross-sectional study, so it did not fully capture the caregiving experience throughout COVID-19, but rather provides a "snapshot" of a specific point at the beginning of the pandemic. There have been numerous changes to care provision and FCGs' experiences, which are not addressed in this study. Another potential limitation is not including the level of cognitive impairment of the family member as one of the variables. Increased cognitive impairment of the person living with dementia has been shown to increase the strain of the caregiving role, but this potential influencing factor was not controlled for in the analysis. Finally, the sample size is small and does not account for the diversity in the FCGs. Future studies could examine how COVID-19 impacted FCGs for people living with dementia from diverse backgrounds.

Conclusion

Understanding the caregiving experience during the COVID-19 pandemic and the impact it has had on FCGs is a critical consideration given the invaluable service they provide. An aging population, longer life expectancies, and better medical care have contributed to the increasing reliance of the health care system on FCGs. Even prior to COVID-19, FCGs provided the majority of care for people living with dementia in the community. The COVID-19 pandemic exacerbated the challenges faced by FCGs. COVID-19 public health measures led to considerable changes in care provision, resulting in the need for FCGs to significantly adapt their caregiving routine to accommodate these ongoing changes. The public health measures also had a significant impact on the access FCGs had to essential health and social support services. Because of social isolation, FCGs were providing higher levels of care and more hours of care with fewer services and less support.

The reliance people living with dementia have on their FCGs and the increasingly difficult challenges in care provision brought on by COVID-19 were shown to be significantly amplified. There is a critical necessity to identify and understand needed and accessible supports and care provision resources for FCGs, to promote their health and ensure that they are able to continue caring for their family member living with dementia. FCGs are heterogeneous group and a significant unpaid labour force that governments rely on to reduce the demands on the formal health care system. In this reliance, there is an assumption that FCGs are both available and able to fulfill the requirements of the caregiving role. It is hoped that by addressing the recommendations identified by the FCGs, their individual caregiving efforts will be better supported, which will add to the sustainability of the formal health care system that relies upon them collectively.

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Appendix: Focus Group Guiding Questions

What has your experience providing care been during the COVID-19 pandemic?

How has COVID-19 impacted your caregiving routine?

Have you noticed any changes in your family member during the COVID-19 pandemic?

What has been your biggest worry during the COVID-19 pandemic?

Have you experienced any relief or positive experiences during the COVID-19 pandemic?

Did you experience any difficulties in coordinating care because of COVID-19 restrictions?

What resources would most benefit you right now?

Any overall suggestions for ways to support you during this health crisis?