



International Journal of Nursing and Health Care Science

Research Article

McGhan G, et al. J Int J Nurs & Healt Car Scie 04: 2024-323

Gap Analysis of Family Caregivers' Needs during a Global Pandemic

Gwen McGhan, RN, PhD, GNC(c)^{1#}, Deirdre McCaughey, PhD, MBA², Kristin Flemons³, Jasneet Parmar, MBBS, M.Sc., MCFP (COE)⁴, Sharon Anderson, MEd., MSc., PhD.⁵

Submission Date: 23 March, 2024

Accepted Date: 11 April, 2024

Published Online: 15 April, 2024

^{1#}Faculty of Nursing, University of Calgary, Alberta, Canada

²Department of Community Health Sciences, Cumming School of Medicine, University of Calgary, Alberta, Canada

³Indigenous Wellness Core, Alberta Health Services, Alberta, Canada

⁴Family Medicine, University of Alberta, Alberta, Canada

⁵Faculty of Medicine and Dentistry, University of Alberta, Alberta, Canada

How to cite this article: McGhan G, et al. (2024) Gap Analysis of Family Caregivers' Needs during a Global Pandemic. *Int J Nurs & Healt Car Scie* 04(05): 2024-323.

#Corresponding author: Gwen McGhan, RN, PhD, GNC(c), Associate Professor, Faculty of Nursing, University of Calgary, 3204, 2500 University Dr. NW, Calgary, Alberta, T2N 1N4, Canada

Abstract

COVID-19 has increased burden on family caregivers for people living with dementia, while simultaneously limiting the resources available to them. Our study surveyed family caregivers to assess their needs and generate recommendations to inform policies about access to essential resources and support services during a global pandemic. Using community-based research strategies, we engaged key community stakeholders across a Western Canadian province. The study used mixed methods with a sequential triangulation design, in which survey results informed the qualitative data collected from focus groups. A total of 284 family caregivers participated in the survey, with an average age of 57 years. The majority of family caregivers were women (78.2%), 37.8% were spouses and 53.7% were adult children. Respondents reported feeling more isolated (71.4%), more strain (62.9%), decreased quality of life (67.8%), and worse physical health (47.3%) and mental health (59.1%) compared to pre-pandemic. The main challenge to the caregiving routine was the restriction of resources such as respite and home care, which were no longer available. Family caregivers reported an increase in caregiving responsibility and less access to services resulting in their family member living with dementia experiencing a decline in overall wellness and function. Three main themes emerged including: 1) the impact of COVID-19 on caregiving; 2) caregiving dyad outcomes; and 3) challenges with system navigation. Our study provides foundational knowledge to generate evidence-informed practices to address the gaps in resources and services that best support care provision beyond the COVID-19 pandemic and in future public health emergencies.

Keywords: Caregiving; COVID-19; Dementia; Resources

Background

COVID-19 and its resulting public health measures led to considerable changes in care provision across the care continuum in the community, supportive living and long-term care. Those significantly impacted by the changes were family caregivers and people living with dementia for whom they provide care (the caregiving dyad). Dementia is a broad term utilized to identify people who have progressive neurocognitive impairment. It is a disabling and challenging disease as well as one of the most prevalent chronic conditions, currently affecting an estimated 564,000 Canadians [1] and approximately 51 million people worldwide [2,3]. Women are disproportionately impacted by dementia as they represent two-thirds of clinically diagnosed cases [4]. Over 90% of people living with dementia experience responsive behaviors including apathy, depression, anxiety, aggression, agitation, and psychosis [5]. These symptoms can result in declines in physical and cognitive functioning, poor quality of life, burden for their caregivers, and an increased risk for physical abuse for the person living with dementia [5,6].

The costs of dementia to the Canadian health care system are staggering, with combined health care system and out-of-pocket costs being \$10.4 billion per year with this cost expected to increase by 60% to \$16.6 billion by the year 2031 [1]. This figure does not include the additional system costs associated with managing COVID-19 nor the unpaid labour of family caregivers, who are estimated to contribute \$97.1 billion yearly, which represents 32.2% of national expenditures on health care [7].

Globally, family caregivers make up a significant portion of the population, including 2.7 million in Australia (or 11% of the total population); 8.1 million in Canada (28%); 6.5 million in the United Kingdom (10.3%); and 43.5 million in the United States (13%) [8]. They are key partners in the health care system, as they provide up to 90% of the care for people living with dementia in the community [9] and assist with 30% of the care in congregate care [10]. Family caregivers play a pivotal role in engaging, empowering and caring for people living with dementia and are a critical factor enabling them to remain in the community [11,12]. We define a family caregiver, also known as a care partner, as an unpaid individual (e.g., a spouse, partner, family member, friend, or neighbour) involved in assisting people living with dementia with activities of daily living and/or everyday tasks. Typically, family caregivers are responsible for providing both emotional and physical care as well as organizing and coordinating services on behalf of the person living with dementia [13]. As the disease progresses, people living with dementia require more assistance with activities of daily living, increasing family caregivers' stress and fatigue, thus reducing their ability to support the person living with dementia [5]. Family caregiving disproportionately impacts women, as upwards of 75% of all caregivers are women, and they spend as much as 50% more time providing care than men [9,14].

Increased strain in the caregiving role has been associated with premature institutionalization and unmet needs for people living with dementia [15]. Even prior to COVID-19, family caregivers were often providing care without adequate or affordable resources [13] with 85% of family caregivers for people living with dementia reporting unmet needs in their care provision role [16]. The challenges of caregiving have been exacerbated by COVID-19, with family caregivers experiencing increased anxiety, depression, fatigue, sleep disturbance and financial worries, with those caring for people living with dementia reporting more adverse outcomes [13]. Family caregivers' mental health has declined during the pandemic and social isolation, which increases the risk for morbidity and early mortality Family Caregiver Alliance [14] was intensified by the COVID-19 public health measures [17-19]. Family caregivers are heterogeneous group and a significant unpaid labour force that governments rely on to reduce the demands on the formal healthcare system. However, there has been increasing awareness of the need to support sustainability of family caregivers in their caregiving role [20]. As such, the purpose of our study was to examine: 1) COVID-19 public health messaging and knowledge; 2) access care provision supports and resources during the pandemic and; 3) the outcomes for the caregiving dyad.

Methods

Design

The study employed a mixed methods triangulation design. Quantitative (online survey) and qualitative (focus group) data were collected sequentially, and designed to be mutually informing and analyzed in relationship to each other [21]. The results of the two analyses were compared and contrasted leading to an overall interpretation of the results [22]. Using community-based research strategies, we engaged key community stakeholders across a Western Canadian province. The Community Advisory Committee (CAC) was comprised of members from our partner organizations including Dementia Network Calgary, Alzheimer Society of Calgary, Alzheimer Society of Alberta and Northwest Territories, and Alberta SPOR SUPPORT (AbSPORU), as well as with family caregivers from our study population. The CAC guided the study design, revisions of our survey questions, provided input on focus group discussion guides, and aided with the interpretation and validation of the study findings.

The theoretical framework underpinning the study was Hobfoll's Conservation of Resources (COR) Model [23-26]. COR is an integrated stress theory, which places equal emphasis on the environmental and internal aspects of the stress process [23]. In this model, the focus is on the resources that preserve well-being in the face of stressful situations [23,25]. Resources in this model can be divided into formal and informal. For the purposes of this study, we focused on formal resources such as: 1) respite care; 2) caregiver support groups; 3) adult day programs; 4) transportation services; and 5) community support services. Using COR allowed for the examination of how the changing environmental factors during a public health emergency, such as COVID-19, affected the resources needed and accessible to family caregivers. It also provided a foundation for understanding the outcomes of 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_REN3).

Sampling, Data Collection and Analysis

The study was conducted in a Western Canadian province and represented the five health care zones within the province. Voluntary, informed consent was obtained from all study participants. Participant eligibility included family caregivers over the age of 18 providing care for a person living with dementia during the COVID-19 pandemic, and the ability to read and write English. Our CAC partners assisted with distribution of the online survey through their networks using websites, newsletters, social media, and e-mail addresses of organizational contacts. Qualtrics was used to develop and deliver the online survey and included well established scales [27] (Table 1). The quantitative data was analyzed using IBM Statistical Package for Social Sciences software (IBM SPSS) version 26 using descriptive statistics.

Source	Survey Questions
[28]	Questions about the impact of the COVID-19 pandemic on (1) the living situation of the caregiver and the person with dementia they care for and (2) the caregiving routine were adapted from this study.
[29]	This scale was adapted to evaluate changes in the ability of the person living with dementia during the COVID-19 pandemic.
[30]	Several questions were adapted from this survey to evaluate participants COVID-19 related knowledge and the sources of information used for COVID-19 updates.
[31]	Questions were adapted from this study to assess participants evaluation of the Alberta Public Health messaging regarding COVID-19 and their care resource utilization change during the COVID-19 pandemic.
[32]	A well validated short form version of the Zarit Caregiver Burden Scale was adapted to examine levels of caregiver burden.
[33]	These questions were adapted to evaluate the family caregiver's perception of changes in neuropsychiatric symptoms in the person with dementia they care for during the COVID-19 pandemic.

Table 1: Survey Questions Sources.

Focus group participants were recruited from the survey respondents with a question prompting participants to provide their e-mail address if they were interested in participating in a follow up focus group. For the focus groups, participants were grouped based on their position along the care continuum (community, assisted/supportive living, long-term care) as well as place of residence (urban, suburban, and rural). Focus groups were conducted online using videoconferencing and teleconferencing software, lasted 60-90 minutes and were recorded and transcribed verbatim. NVivo 12 data analysis software was used for qualitative data management. Two research team members with expertise in qualitative methods independently and repeatedly reviewed the transcripts to generate initial codes. Using Braun and Clarke's method for thematic analysis, the focus group transcripts were iteratively examined to identify concepts that were compared for similarities and differences [34,35]. In the next phase, codes that were conceptually similar were grouped forming the main themes within the data. The process was repeated until data saturation occurred and no new or relevant information was gleaned from the data, at which point the themes were refined and named [34]. The consolidated criteria for reporting qualitative research (COREQ) checklist, which is a comprehensive checklist for reporting qualitative studies, was used as a guide for analyzing and interpreting the focus group results [36].

Results

Quantitative Results

284 family caregivers participated in the survey, with an average age of 57 years. The majority of family caregivers were women (78%), 38% were spouses and 54% were adult children. Family caregivers were providing care across the continuum including community (48%), assisted/supported living (21%), long-term care (28%) and at a distance (5%). Family caregivers' place of residence were urban (57%), suburban (24%) and rural (19%), which approximately represents the population of the province. Forty-eight% of the participants had been providing care to their family member living with dementia for more that four years, with 25% spending more than 40 hours per week providing care (Table 2).

	N	%
<i>Gender</i>		
Female	215	78.2
Male	56	19.7
Other	4	1.4
<i>Age</i>		
Less than or equal to 50 years	36	13.2
51-60 years	72	26.4
61-70 years	98	35.9
71-80 years	48	17.6
Greater than 80 years	19	7
<i>Marital Status</i>		
Single	32	11.6
Married/common law	218	79
Divorced/separated	11	4
Widowed	15	5.4
<i>Ethnicity</i>		
Caucasian	259	94.2
Aboriginal/Indigenous	4	1.5
Asian	7	2.5
Other	4	1.5
<i>Length of Time as a Caregiver</i>		
Less than 1 year	17	6
1-2 years	42	14.9
2-4 years	88	31.2
Greater than 4 years	135	47.9
<i>Area Lived In</i>		
	N	%
Urban	157	57.1
Suburban	67	24.4
Rural	51	18.5
<i>Self-Health Rating Compared to Others</i>		
Poor	21	7.6
Fair	58	21.1
Good	100	36.4
Very Good	84	30.5
Excellent	12	4.4
<i>Ability to Continue Caring for Person Living with Dementia</i>		
PLWD no longer needs care support	28	10.2
Yes, definitely	130	47.3
Yes, somewhat	108	39.3
No	9	3.3
<i>Person Living with Dementia - Gender</i>		
Female	167	58.8
Male	106	38.5
Other	2	0.8
<i>Person Living with Dementia - Age</i>		
51-60 years	4	1.5
61-70 years	31	11.3
71-80 years	67	24.4
Greater than 80 years	173	62.9
* Note: n = 284. Columns may not total exactly due to rounding and/or missing information.		

Table 2: Participant Demographics.

COVID-19 Knowledge and Policies

For public health messaging, 46% of family caregivers rated overall COVID-19 messaging as good-excellent. The health messaging areas that family caregivers rated as needing improvement included: 1) what to expect in the future (63%); 2) where to get information on community services (65%) and care provision for people living with dementia (77%); and 3) how and when to get the vaccine (60%). The top sources for public health information were TV (66%) and online news/websites (51%). Conversely, 74% of the family caregivers reported never using their healthcare providers for information. The vast majority of the respondents (85%) indicated that the public health measures had a negative impact on their caregiving with 68% being willing to be trained on personal protective equipment usage to improve access to their family member in congregate care.

Provision of Care during COVID-19

The main challenge to the caregiving routine was the restriction of resources resulting in a decrease of resource utilization as required resources and services, such as respite and home care, were no longer available. For their caregiving routine, 94% of the family caregivers reported their caregiving routine was affected by pandemic, with 43% reporting they were spending more time caregiving and 74% having decreased ability to access needed resources and supports. Fifty-nine% experienced difficulties navigating the health care system. The two most needed resources not available during the pandemic were adult day programs and future planning for the care of people living with dementia.

Outcomes for Family Caregivers and People Living with Dementia

Respondents reported feeling more isolated (71%), more strain (62%), decreased quality of life (68%), and worse physical health (47%) and mental health (59%) compared to pre-pandemic. Family caregivers also reported feeling increased guilt (69%) and stress (61%) and that they should be doing more for their family member living with dementia. Family caregivers reported an overall decrease in the wellness of their family member living with dementia and an increase in responsive behaviours such as anxiety (62%), depression (61%), apathy (61%), nighttime activity (56%) and agitation/aggression (55%).

Qualitative Results

The follow up focus groups were informed by the survey data as well as the CAC. Twenty-six family caregivers participated in one of six focus groups which were divided across the care continuum; community (50%), assisted or supportive living (35%) and long-term care (15%). Most family caregivers were caring for their parents or parents-in-law (65%), followed by a spouse or partner (31%). The majority of participants were women (84%), with an average age of 64 years. Most of the participants lived in urban (52%) or suburban areas (28%), with 20% living in rural areas. For the family members living with dementia, the majority were also women (60%) with an average age of 84. From the focus groups with family caregivers, three main themes emerged including: 1) the impact of COVID-19 on caregiving; 2) caregiving dyad outcomes; and 3) challenges with system navigation.

The Impact of COVID-19 on Care Provision

Focus groups highlighted that accessing services and resources during COVID-19 was overly burdensome. Family caregivers reported an increase in caregiving responsibility while at the same time having less access to resources and services needed to support their caregiving routine as highlighted by the following:

...But all of that just stopped. They just, it all ended. It was just cold turkey.

Another family caregiver shared their similar experience of having their access to pre-COVID-19 resources stopped:

...things were going along and all of a sudden, the pandemic happened. Everything that had been provided to us was turned off. No more visits for bath. No more adult dayprograms. So I was sort of left on my own.

Resources needed but not available during the pandemic were respite, day programs, and care assistance, followed by opportunities for physical activity and caregiver support groups and mental health support. Family caregivers also noted the increased need to be an advocate for their family member living with dementia in order to access needed services and resources:

There's no winning. If they were in care or if they're on their own or if they're living with you there is no winning. It's all really, really hard. And, there's only so much that you can support and provide because you can't do it all. As much as you want to, you can't.

Adding to the challenge was the increasing difficulty of engaging in this advocacy as illustrated by the following:

We're like an ombudsman for our family, for our people that are suffering with this. And, we have to advocate and through trial and error, we have to find out which questions to ask, and who to ask them of and how to stitch all those things together.

Caregiving Dyad Outcomes

The second theme to emerge from the focus groups was caregiving dyad outcomes where family caregivers discussed the changes for themselves as well as their family member living with dementia. Family caregivers reported that their burden increased substantially during the pandemic and noted the relationship between the impact of COVID-19 and the negative outcomes for themselves:

It was just incredibly stressful. I feel like I've aged ten years in one and a half years.

It was not just the individual family caregiver who was impacted but the other family members as well:

We as a unit were in crisis because we're trying to cope with thinking about what's happening to our parents. Not being able to see it, and even what they're describing on the phone. It's just, it was heart wrenching. So we were in crisis too.

Unsurprisingly, social isolation was also as a key concern reported by family caregivers as highlighted by:

When things would get really tough with my mother and she was having a really bad day and I had no break, then I would really miss the socialization.

Family caregivers were also concerned with how social isolation was affecting their family member living with dementia:

Having to stay in her room cause she was very social when she first moved into there and it was very difficult for her to be isolated like she was. And, her dementia definitely worsened.

One family caregiver expressed their concern this way:

You have to ask yourself, was it worth it for her to be locked up? Was it worth it to be locked up and be separated from us. And in the end she was afraid, she was scared to death. I don't know. It's just one of those situations. None of us are ever gonna know. And hindsight is 20/20. And that's my experience.

Another family caregiver noted the change in their family member with the following:

Due to the isolation and lack of opportunity for social contact my wife's Alzheimer's progressed more in those few months than it did in the previous three or four years.

Participants also reported seeing notable decline in the person living with dementia, in terms of mental health, cognitive function and general quality of life.

There has been a big decline in my mom's cognitive abilities over the last 16 months. I'm sure it's partially because I know time is a factor but I think it's also because her day programs were gone.

Family caregivers also expressed gratitude for the efforts of the health care providers and for the care provided to their family members but still noted concerning changes:

Now I will say this, the particular facility he's in, I am blessed that he is in that particular facility. And, I know they were doing their best, they became family to all the residents there. It wasn't just him, they tried to do everything they could do to make sure that there was that human contact but it's not the same. So in my case, I am his sole provider. I am his sole family. And so for us not to be able to see each other, that really hit him. And when I was finally able to go and have a window visit, it was shocking to me to see how much he had aged in that period of time. He looked very drawn.

Challenges with System Navigation

The third theme to emerge over the course of the focus groups was the difficulty of navigating the health care system for family caregivers during the pandemic. Issues such as poor continuity of care and the fragmentation of programs and resources contributed to the complexity of providing care during COVID-19 as illustrated by the following:

Nobody talks to one another, nobody knows...there's no centralized access to even act as a hub and a spoke.

Another family caregiver expressed their difficulty with navigation of the health care system this way:

The system is broken, the systems thinking of this whole program. Individually I think the programs would probably be pretty good but they've got to be integrated.

Difficulties with finding referrals or knowing what was available were common in these discussions as highlighted by the following:

And I've had other friends who were suddenly put into the caregiving role... they don't even know where to turn and these are capable people who are just spinning around like tops because there's no central resource, there's no central help, there's nothing.

Communication issues amongst health care providers was also highlighted as contributing to the stress of care provision:

Our case manager doesn't talk to the doctor... I have been pleading and being a squeaky wheel for a year and half trying to get them to talk to each other. Something happens in the doctor's office, I have to phone the homecare manager. Sometimes here I have to phone the homecare case manager and I have to phone the doctor. And so, that's where I get very frustrated because it's time consuming.

One family caregiver summed it up this way:

The problem isn't the pandemic, the problem is the system.

Discussion

For family caregivers, the pandemic impacted almost every dimension of their lives, from their own risk of becoming ill to their access to resources and support services for care provision. COVID-19 contributed to the complexity of the caregiving role, while at the same time there was an increased reliance of the health care system on family caregivers. Family caregivers have reported providing an average of 10 additional hours of care per week, while at the same time providing higher levels of care due to reduction or closure of formal care provision resources [37,38]. The family caregivers in our study also reported that limited access to supportive care resources and services including homecare and community programs had a negative impact on themselves as well as care provision for their family member living with dementia.

The challenges created by COVID-19 and the resulting public health measures affected family caregivers across the care continuum. In the community, family caregivers for people living with dementia needed to adapt their caregiving routine to address the limited access to supportive care resources and services like homecare and adult day programs [27]. In assisted/supportive living and long-term care, family caregivers were restricted in their ability to participate in care provision due to strict no-visitor policies that were meant to minimize infection in congregate housing settings [39]. COVID-19 has intensified negative outcomes for both members of the caregiving dyad. Family caregivers reported increased stress and greater challenges in care provision while people living with dementia experienced decreased physical and mental health as well as an increase in responsive behaviours. Additionally, family caregivers and people living with dementia have experienced significant suffering due to loss, loneliness and death [17,40,41]. In our study, family caregivers reported feeling more isolated, a decreased quality of life as well as worse physical and mental health. These negative outcomes were compounded by concern for their family member living with dementia and witnessing their overall decline of wellness and functional ability.

COVID-19 and the resulting public health measures disrupted the ways in which family caregivers and their family members engaged with the health care system [42]. Trying to navigate a fragmented system was found to contribute family caregivers' strain and frustration in our study. The health care system was disjointed prior to COVID-19 but the pandemic only made trying to locate required resources and support services more complicated and time consuming [27].

Recommendations

As the Canadian health system is unsustainable without the work of family caregivers [43], there is a need to develop recommendations to best support the caregiving dyad now as well to better prepare for future public health emergencies. The following recommendations are based upon the suggestions from family caregivers in our study.

Recommendation 1: Provide information tailored to the needs of specific vulnerable populations, including family caregivers. Information on how to provide care during a public health emergency; best ways to provide applicable information to people living with cognitive impairment; and how and when caregiving resources and support services may be adapted, cancelled and/or reinstated should be considered.

Recommendation 2: Focus on building family caregivers' capacity. Provide education for family caregivers on the trajectory of dementia and what to expect at each stage of the disease process. Provide targeted supports and services to address the heterogeneous needs in the caregiving role.

Recommendation 3: Provide support in navigating the healthcare system. Re-imagining how resources and services are used and integrated is needed, with a navigation system for family caregivers having the potential for reducing fragmentation and improving support for the caregiving dyad.

As one family caregiver summarized:

It's a good lesson...we obviously need to have these resources in place ahead of time. So if this happens again, and it may very well happen again, that we consider who are the vulnerable people in our society and we protect them first.

Limitations

When interpreting the results of this study, there are limitations to consider. As this is a cross-sectional study, it only provides only a snapshot of time during the COVID-19 pandemic. There were changes in the caregiving experience from the initial to successive waves of the pandemic and these changes were not captured in this study. As level of cognitive impairment for the person living with dementia can have a significant impact on the experience of care provision not including this important information is another limitation of the study. The sample size for the study is small and does not represent the full diversity of family providing care to people living with dementia across the care continuum. As such, the level of generalizability and transferability is limited.

Conclusion

Understanding the caregiving experience during the COVID-19 pandemic and the impact it has had on family caregivers is a critical consideration given the invaluable service they provide. The COVID-19 pandemic and its impact on access to essential health and social support services led to considerable changes in care provision, resulting in the need for family caregivers to significantly adapt their caregiving routine to accommodate these ongoing changes. Due to social isolation, family caregivers were providing higher levels of care and more hours of care with fewer services and less support. The impact on quality of life for both members of the caregiving dyad from the pandemic is ongoing, and will have ramifications on them and the systems that support them for years to come [44]. Alleviating these impacts requires shifting the way we think about providing information, resources and supports, as captured by the following family caregiver's comments:

We don't want to reset the system back to what it was before the pandemic. The pandemic has had its challenges and some rather unfortunate things have happened, but it did highlight a lot of things...that pre-existed it. I think that's the very, very strong message strategically speaking, because there are a lot of gaps and a lot of shortcomings about this. And this is a very, very large societal problem that is only going to get bigger.

Author Contribution Statement

GM and DM conceived research. GM, DM, KF, JP, and SA contributed to research design. GM, DM and KF analyzed data. GM wrote the manuscript. All authors read and approved the manuscript.

Acknowledgments

We thank the Drummond Foundation for their generous financial support of this study. We also thank our Community Advisory Committee, which included members from the Alzheimer Society of Calgary, Dementia Network Calgary Alzheimer Society of Alberta and Northwest Territories, Caregivers Alberta, and Alberta Strategy for Patient-Oriented Research Unit for their instrumental guidance through all stages of the research study design, implementation and interpretation of the findings. Finally, a thank you to all the family caregivers who provide care for their family member living with dementia and especially to those who participated in our study and shared the gift of their time and knowledge with us.

References

1. Chambers LW, Bancej C, McDowell I (2016) Prevalence and Monetary Costs of Dementia in Canada (p. 70). The Alzheimer Society of Canada.
2. Institute for Health Metrics and Evaluation (2019) Global Burden of Disease Study 2019 (GBD 2019) Data Resources.
3. World Health Organization (2020) Dementia Fact Sheets.
4. National Alliance for Caregiving. Caregiving in the U.S (2009) National Alliance for Caregiving in collaboration with AARP; 2009: 79.
5. Kolanowski A, Boltz M, Galik E, et al. (2017) Determinants of behavioral and psychological symptoms of dementia: A scoping review of the evidence. *Nursing Outlook* 65: 515-529.
6. Toot S, Swinson T, Devine M, et al. (2017) Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis *International Psychogeriatrics* 29: 195- 208.
7. Eales J, Fast J, Duncan KA, et al. (2022) Value of Family Caregiving in Canada. University of Alberta and University of Manitoba.
8. International Alliance of Carer Organizations (2018b) Carer Needs.
9. Sinha M (2013) Portrait of Caregivers, 2012. Statistics Canada.
10. Coe NB, Werner RM (2022) Informal Caregivers Provide Considerable Front-Line Support In Residential Care Facilities And Nursing Homes. *Health Affairs* 41: 105-111.
11. Holroyd-Leduc J, Resin J, Ashley L, et al. (2016) Giving voice to older adults living with frailty and their family caregivers: Engagement of older adults living with frailty in research, health care decision making, and in health policy. *Research Involvement and Engagement* 2.

12. Holroyd-Leduc J, McMillan J, Jette N, et al. (2017) Stakeholder meeting: Integrated knowledge translation approach to address the caregiver support gap. *Canadian Journal on Aging / La Revue canadienne du vieillissement* 36: 108-119.
13. Schulz R, Beach SR, Czaja SJ, et al. (2020) Family caregiving for older adults. *Annual Review of Psychology* 71: 635-659.
14. Family Caregiver Alliance (2019) Caregiver Statistics: Demographics.
15. Estabrooks CA, Straus SE, Flood CM, et al. (2020) Restoring trust: COVID-19 and the future of long-term care in Canada. *FACETS* 5: 651-691.
16. Black BS, Johnston D, Rabins PV, et al. (2013) Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study. *Journal of the American Geriatrics Society* 61: 2087-2095.
17. Cohen G, Russo MJ, Campos JA, et al. (2020) Living with dementia: Increased level of caregiver stress in times of COVID-19. *International Psychogeriatrics* 32: 1377-1381.
18. Holt-Lunstad J, Smith TB, Baker M, et al. (2015) Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspectives on Psychological Science* 10: 227-237.
19. Small B (2016) Reducing Caregiver Isolation. Family Caregivers of British Columbia.
20. Hollander MJ, Guipig L, Chappell NL (2009) Who cares and how much? The imputed economic contribution to the Canadian Healthcare System of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly* 12.
21. Onwuegbuzie AJ, Combs JP (2011) Data Analysis in Mixed Research: A Primer. *International Journal of Education* 3(1).
22. Shojania KG, Grimshaw JM (2005) Evidence-based quality improvement: The state of the science. *Health Affairs (Millwood)* 24: 138-150.
23. Hobfoll SE (1989) Conservation of resources: A new attempt at conceptualizing stress. *American Psychologist* 44: 513-524.
24. Hobfoll SE (1998) *Stress, Culture, and Community*. 1st ed. Springer US.
25. Hobfoll SE (2001) The Influence of Culture, Community, and the Nested-Self in the Stress Process: Advancing Conservation of Resources Theory. *Applied Psychology: An International Review* 50: 337-421.
26. Hobfoll SE, Halbesleben J, Neveu JP, et al. (2018) Conservation of Resources in the Organizational Context: The Reality of Resources and Their Consequences. *Annual Review of Organizational Psychology and Organizational Behavior* 5: 103-128.
27. McGhan G, McCaughey D, Flemons K (2023) Examining the Needs of Family Caregivers of People Living with Dementia in the Community during the COVID-19 Pandemic. *Canadian Journal on Aging / La Revue canadienne du vieillissement* 42: 485-494.
28. Irani E, Niyomyart A, Hickman RL, Jr (2021) Family Caregivers' Experiences and Changes in Caregiving Tasks During the COVID-19 Pandemic. *Clinical nursing research* 30: 1088-1097.
29. Bucks RS, Ashworth DL, Wilcock GK, et al. (1996) Assessment of activities of daily living in dementia: Development of the Bristol Activities of Daily Living Scale. *Age Ageing* 25: 113-20.
30. COVID-19 Snapshot Monitoring in Canada (COSMO Canada) (2022) Monitoring Citizens' Perceptions, Knowledge, and Behaviours relating to the Pandemic (Part II) *PsychArchives*.
31. Galvin JE, Duda JE, Kaufer DI, et al. (2010) Lewy body dementia: caregiver burden and unmet needs. *Alzheimer disease and associated disorders* 24: 177-181.
32. Zarit SH, Reever KE, et al. (1980) Relatives of the impaired elderly correlates of feelings of burden. *The Gerontologist* 20: 649-655.
33. Cummings JL (1994) The neuropsychiatric inventory questionnaire. *Neurology* 44: 2308-2314.
34. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77-101,
35. Nowell LS, Norris JM, White DE, et al. (2017) Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods* 16.
36. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19: 349-357.
37. Carers UK. *Caring Behind Closed Doors: Forgotten Families in the Coronavirus Outbreak* (2020).
38. Hoffman GJ, Webster NJ, Bynum JPW (2020) A Framework for Aging-Friendly Services and Supports in the Age of COVID-19. *Journal of Aging & Social Policy* 32: 450-459.
39. Hindmarch W, McGhan G, Flemons K, et al. (2021) COVID-19 and Long-Term Care: the Essential Role of Family Caregivers. *Canadian geriatrics journal: CGJ* 24: 195-199.
40. Baker HA, Safavynia SA, Evered LA (2020) The "third wave": impending cognitive and functional decline in COVID-19 survivors. *British Journal of Anaesthesia* 126: 44-47.
41. Tupper SM, Ward H, Parmar J (2020) Family Presence in Long-Term Care During the COVID-19 Pandemic: Call to Action for Policy, Practice, and Research. *Canadian Geriatrics Journal* 23: 335-339.
42. Semere W, Makaroun LK, Beach S, et al. (2022) Family caregivers navigating the health care system: Evolving roles during the COVID-19 pandemic. *Families, systems & health : the journal of collaborative family healthcare* 40: 268-273.
43. Romanow R (2002) Building on Values: The Future of Health Care in Canada. *Commission on the Future of Health Care in Canada* 356.
44. Flemons K, McGhan G, McCaughey D (2022) Family Caregiving for People Living With Dementia During COVID-19: A Thematic Analysis. *Journal of Family Nursing* 28: 219-230.