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Caregiver Perspectives of Aging in Place with Dementia: A Qualitative Exploration of Barriers Using the Social Ecological Model

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Abstract

Most persons living with dementia in Canada reside at home, relying on support from family and/or friends as caregivers. Evidentially, knowledge gaps exist when trying to understand how caregivers and persons living with dementia can be better supported in their community and health care environments. This research examined the effect of aging in place with a focus on providing a comprehensive understanding of the barriers to aging in place for persons living with dementia and their caregivers using the social-ecological model. Fourteen caregivers were recruited to participate in one-on-one semi-structured interviews. The subsequent theme, *they do not make it easy*, emphasizes issues faced with community and societal domains of aging in place care. These findings shed light on the unmet needs of persons living with dementia and their caregivers while aging in place, as well as the need to address systemic barriers to sincerely promote aging in place for *all* persons.

Résumé

Au Canada, la plupart des personnes atteintes de démence vivent à domicile et dépendent de l'aide de leur famille et/ou de leurs amis. Il existe manifestement des lacunes dans les connaissances lorsqu'il s'agit de comprendre comment mieux soutenir les aidants et les personnes atteintes de démence dans leur communauté et leurs milieux de soins de santé. Cette recherche basée sur le modèle socio-écologique a examiné l'effet du vieillissement à domicile en vue de fournir une compréhension globale des obstacles à ce mode de vie pour les personnes atteintes de démence et leurs aidants. Quatorze aidants ont été recrutés pour participer à des entretiens individuels semi-structurés. Le thème qui en est ressorti, « *ils ne facilitent pas les choses* », a mis en évidence les problèmes rencontrés dans les domaines communautaire et sociétal des soins aux personnes âgées qui vivent chez elles. Ces résultats mettent en lumière les besoins non satisfaits des personnes atteintes de démence qui vieillissent à domicile et de leurs aidants, ainsi que la nécessité de remédier aux obstacles systémiques au vieillissement à domicile afin de le promouvoir sincèrement pour *toutes et tous.*

Introduction

In the past decade, approximately six million Canadians were aged 65 and older, accounting for roughly 15 per cent of the population. In the coming decade, this number will surpass ten million and older adults will comprise 25 per cent of the population (CIHI, 2023a). This shift in the composition of the Canadian population has been defined as 'uncharted territory' (CIHI, 2023b, p. 1), and it is clear that the Canadian government and health care system are not equipped for the needs of an aging population (Milhaildis, 2023). The COVID-19 pandemic called into question the capabilities of the current landscape of health care and support services for older adults in Canada, which has specific implications for the health and quality of life for this age group (Steele et al., 2023). Thus, it is paramount that strategies are developed that allow *all* older adults to maintain their independence and quality of life regardless of any health conditions they may have. Aging in place may be one such strategy.

Aging in place refers to 'having access to services and the health and social supports needed to live safely and independently in your home or community for as long as you wish and are able' (Government of Canada, 2023, p. 1). Often contrasted with institutionalized care settings (e.g. long-term care, assisted living), aging in place allows older adults to maintain their social connections, routines, and familiarity with their environments while prioritizing independence and autonomy (Ratnayake et al., 2022). Research has demonstrated that most older adults in Canada wish to and are aging in place (CIHI, 2023a), and that aging in place is a primary component of aging well (Jakobi, 2022). However, there are challenges to the effective implementation of aging in place care in Canada, particularly as it relates to persons living with dementia and their caregivers – the latter being instrumental to the ability to age in place (CIHI, 2023a). In 2020, approximately 600 thousand people were living with dementia in Canada; however, by 2050, that number is projected to increase to over 1.7 million (Alzheimer Society of Canada, 2022).

Currently, 61 per cent of persons living with dementia in Canada are living at home, compared to approximately 94 per cent of older adults in general (CIHI, 2023a). There are a variety of reasons persons living with dementia wish to remain in their homes following diagnosis and throughout the trajectory of the disease (Huyer et al., 2020). The preference to age in place is supported by empirical evidence, which has found that aging in place positively affects survival and well-being (e.g. personal, financial, etc.) compared to living in long-term care (McClendon et al., 2006; Soilemezi et al., 2019). However, barriers to aging in place are increasingly evident for all older adults, particularly those living with dementia. Existing literature has explored barriers to aging in place for caregivers and older adults with self-reported cognitive impairments (Mayo et al., 2021); however, none of the participants in the study reported a formal diagnosis of dementia. Barriers to aging in place for this group included memory decline, decreased self-reliance, and social isolation. The barriers outlined in this study were primarily individual factors; thus, less is known about additional factors that impact the ability to age in place for this group. In a study by Thoma-Lürken et al. (2018), various dementia home care experts, such as care managers, nurses, occupational therapists, and assistive technology providers, were interviewed to ascertain barriers for persons living with dementia in the Netherlands. Of the 43 participants, four informal caregivers participated and shared their experiences within the aging in place environment. Barriers cited within this study paralleled those in Mayo et al. (2021) but included additional barriers such as caregiver burden and issues with formal care.

From this research, knowledge gaps are evident when trying to understand the diversity of barriers (beyond the individual) for persons living with dementia and their caregivers in Canada. There is a myriad of factors that may help understand how caregivers and persons living with dementia can be better supported in their communities and by the health care system. Thus, this research examined the effects of aging in place with a specific focus on providing a comprehensive understanding of the barriers to aging in place for persons living with dementia using the social-ecological model. The social-ecological model (Figure 1) exemplifies the complex interconnections between individual, relationship, community, and societal factors. These factors function individually and influence each other in varying ways (Kilanowski, 2017). As such, this framework was used to examine aging in place from the perspectives of caregivers of persons living with dementia. The implications of this research included acquiring knowledge concerning barriers to aging in place for persons living with dementia and their caregivers and providing recommendations for how to address those barriers. This study adds to the current understanding of aging in place for persons living with dementia and their caregivers and can inform the development of future resources and policies for this group.

Methodology

Design

This study was grounded in a constructivist research paradigm, meaning the researchers held the idea that 'reality is constructed in the mind of the individual, rather than an externally singular entity' (Ponterotto, 2005, p.129). Constructivists aim to comprehend subjective experiences by understanding how their own background and knowledge influence their interpretations (Creswell & Creswell, 2018). Further, phenomenology was the theoretical orientation used to guide this qualitative study. As stated by van Manen (1984), 'phenomenology asks for the very nature of a phenomenon, for that which makes a some – 'thing' what it is – as without which it could not be what it is' (p.38). Moreover, a phenomenological study describes the meaning individuals extract from a shared experience (Creswell & Creswell, 2018), in this case,

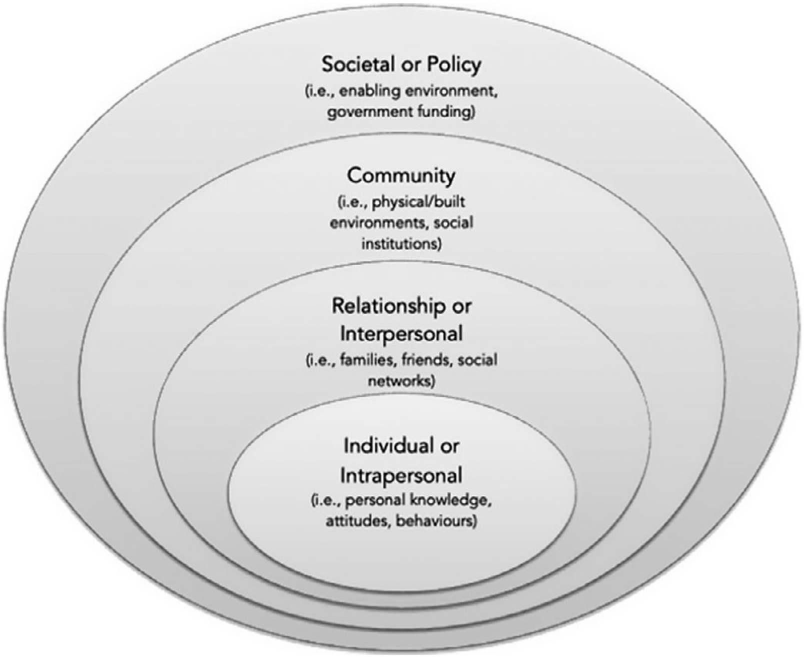

Figure 1. The social-ecological model.

aging in place with dementia. More specifically, interpretive phenomenology was used, which stipulates that the beliefs and interpretations of the researchers may play a role in the research process. van Manen (1984) contends 'the meaning structure of this experience as lived through, is brought back, as it were, and in such a way that we recognize this description as a possible human experience, which means as a possible interpretation of that experience' (p. 44). van Manen (1984) asserts that the phenomena in question (caregiving) are connected to personal experiences, which are then used to examine how individuals make meaning of these experiences, utilizing the words of the individuals themselves. Interpretive phenomenology was the best fit as the theoretical approach for this study, as it allowed for the exploration of the lived experiences of caregivers of persons living with dementia. To do this, 'one must undertake in-depth interviews with people who have directly experienced the phenomenon of interest; that is, they have "lived experience" as opposed to "second-hand experience"' (Patton, 2002, p. 104). Overall, the aim of this study was to understand how caregivers and persons living with dementia experienced aging in place. Phenomenology was best suited to address participants' subjective meaning-making processes and to understand the essence of their lived experience. Alongside interviews, background questionnaires, field notes, and member checks were used as methods of data collection, as they allowed for the true voices of participants to be conveyed and to truly understand the core of their experiences.

Recruitment

Purposeful sampling was utilized for recruitment of eligible caregivers as it allowed for the identification and selection of participants who experienced this phenomenon and thus were considered information-rich and able to impart their knowledge in detail (Creswell & Creswell, 2018). The inclusion criteria for caregivers included: (a) must be a resident of Ontario; (b) must currently provide or have recently provided (within the past year) care to the community-based person living with dementia. Data collection continued until saturation had been obtained, meaning the researchers saw repetition in the interviews and additional data would not enhance the research findings (Patton, 2002).

Ethics

All tools and procedures were approved by the Wilfrid Laurier University Research Ethics Board (REB#8665). After ethics approval was obtained, participants were asked to read and sign an informed consent statement before participating. Further, participants were given the opportunity to ask the primary researcher any questions before, during, and after the process.

Participants

Interviews were conducted with 14 caregivers of persons living with dementia living in Ontario, Canada. Eleven women and three men self-identified as caregivers for one or more persons living with dementia. Various relationships existed between caregivers and persons living with dementia, with eight participants providing care for a parent/step-parent with dementia, five participants providing care for a spouse with dementia, and one participant providing care for a grandparent with dementia. Participants' ages ranged from 22–84, with a mean age of 60 years old. Four of the interviews were retrospective in nature, with caregivers reflecting on the time they spent providing in-home dementia care before they recently (within the last year) transitioned the person living with dementia to long-term care ($n = 3$) or a retirement community ($n = 1$). The remaining 10 participants were providing care in the home at the time of the interview (Table 1).

Data Collection

Each participant took part in a one-on-one semi-structured interview conducted by the primary researcher, which was arranged at a time and place most convenient to the participant (i.e. in person or over the phone). The length of the interview depended on the depth

Table 1. Participant information

Caregiver	Age	Relation to Person Living with Dementia	Caregiving situation
'Georgia'	63	Daughter of person living with dementia	Moved in with her mom while providing care
'Isabella'	63	Wife of person living with dementia	Lives with her husband while providing care
'Morrie'	84	Husband of person living with dementia	Lives with his wife while providing care
'Sam'	60	Daughter of person living with dementia	Lives near her mother, splits care responsibilities among her siblings
'Valerie'	54	Daughter-in-law of person living with dementia	Moved mother-in-law into her house to provide care
'Reid'	49	Son of person living with dementia	Moved mother into his house to provide care
'Riley'	22	Granddaughter of person living with dementia	Lives in her family home with her grandma
'Nancy'	53	Daughter of person living with dementia	Lives in same city as person living with dementia
'Paul'	73	Husband of person living with dementia	Lives with his wife while providing care
'Jen'	56	Daughter of person living with dementia	Moved her mom into her home while providing care, has since transitioned her to a retirement home
'Caroline'	68	Wife of person living with dementia	Lives with husband in their home while providing care
'Bonnie'	62	Daughter of person living with dementia (x2)	Lives in same community as person living with dementia, recently moved her to long-term care
'Dana'	58	Daughter of persons living with dementia (x2), niece of person living with dementia	Lived in same community as person living with dementia, recently moved them into a retirement home nearby
'Bridget'	74	Wife to person living with dementia	Lived in same home as husband, recently moved him to long-term care

Table 2. Example interview questions by levels of the social-ecological model

Level of the SEM	Interview Question
Individual	'What does it mean to you to be a caregiver'?
Relationship	'Describe your relationship with person living with dementia before and after the diagnosis'.
Community	'Please discuss the role community programs, support groups, and/or respite care have played in supporting your/person living with dementia's ability to live at home'?
Societal	'Can you share any specific examples to aid in describing your experience with the health care system as a caregiver supporting an individual living with dementia at home'?

of each participant's responses. On average, interviews were 60 minutes long, with the longest interview being 78 minutes and the shortest being 35 minutes. The questions developed for the interview guide were created specifically to address each level of the social-ecological model (see sample questions in Table 2).

Before each interview, participants were advised that they were able to take breaks, refrain from answering any question(s) if they felt uncomfortable, and/or discontinue the interview at any time. Field notes were utilized before, during, and after interviews to capture the primary researcher's initial thoughts, provide context to the transcripts regarding non-verbal communication and body language, and any additional information pertaining to the interview.

Subsequently, each interview was transcribed verbatim to allow for data analysis to ensue. To maintain the anonymity of participants, pseudonyms were used in place of participants' names. Further, any other information deemed identifying in any way was also deidentified. Data analysis began following each interview in order for the researchers to continuously monitor the information collected, as well as saturation, while continuing to recruit and conduct interviews. After transcribing, each interview was subjected to preliminary analysis, such as examining recurring themes between interviews and highlighting topics for further discussion. Data collection ceased when no new information was acquired, and the researchers felt additional interviews would not add to the quality of the research (Patton, 2002).

Data Analysis

Multiple steps were used to conduct an in-depth analysis of the data collected. Information provided in the background questionnaire aided in offering context for the interviews, thus increasing the credibility of the results. Along with this, field notes and member checking allowed for further contextual information from the interviews and background questionnaires, to add to the richness of the results. As all interviews were emotional, the field notes were useful in noting when and how participants became emotional. Data collection and analysis were performed simultaneously, as it was hoped that it would best allow for the ebbs and flows of this phenomenon to be captured and to monitor saturation. The researchers conducted a step-by-step analysis of the data using Braun and Clarke's framework (2022). These six steps included: (a) familiarization with the data; (b) coding; (c) generating initial themes; (d) developing and reviewing themes; (e) refining, defining, and naming themes; (f) writing up (see Braun & Clarke, 2022, for a detailed description of this framework). Both inductive and deductive analysis was used. Specifically, inductive analysis was used to find patterns, categories, and themes that emerged in the data (Patton, 2002), while deductive analysis was employed when developing themes based on existing literature, levels of the social-ecological model, and knowledge of the interview questions.

Enhancing Rigour

Various strategies were used to enhance the trustworthiness of the data (Lincoln & Guba, 1985). Credibility was obtained through the employment of various research procedures (field notes, member checks, etc.) to enhance integrity, the use of data and investigator triangulation, and peer debriefing of the data. Transferability was obtained through the recruitment of information-rich cases to ensure the integrity of the data (Lincoln & Guba, 1985). Confirmability was met through the use of data and investigator triangulation, engagement in reflexive journaling, and the use of quotes to create and support themes. Dependability was ensured through the use of thick descriptions of methodological steps taken to collect, analyse and interpret results (Lincoln & Guba, 1985).

Results

The overall experience of providing aging in place care to persons living with dementia was described extensively by participants through an exploration of a variety of aspects of dementia caregiving. Community and societal barriers to aging in place with dementia were articulated by all caregivers, pertaining to the lack of support they received, the fear associated with long-term care, and additional issues with health care and community services.

THEY DON'T MAKE IT EASY

This theme pertained to difficulties caregivers faced in providing dementia care in relation to the health care system and community services. The two subthemes were as follows: (a) '*Here until we're dragged-out feet first*', which summarized the concerns caregivers voiced regarding long-term care as an alternative to aging in place, and (b) '*The system is broken*', which explained issues with health systems and community services caregivers and persons living with dementia accessed while aging in place. Each will be discussed in turn.

'Here until we're dragged-out feet first'.

One of the major motivations for persons living with dementia and their caregivers to age in place was their perceptions of long-term care in Canada. The interviews revealed clear issues with the structure and functioning of long-term care. Morrie, who provided dementia care for his wife, explained why they had no interest in long-term care.

> *The idea of going somewhere like a retirement home or long-term care home fills my wife with a certain amount of horror… We're here [in their home] until we are dragged-out feet first. Which will be a bit tricky, because they'll have a long stretch of steps to drag us down [laughs].* ~ **Morrie.**

Most caregivers like Morrie shared persons living with dementia were terrified of the idea of long-term care homes.

> *She was dreading, like having to go to a home or something like that… She knew her situation, because by that time she was diagnosed. So, she was so*

> *happy that we asked her to move in with us. It was just a pure relief.* ~ **Reid.**

Sam, who provided care for her mother, expressed that her personal experiences in long-term care made her quite upset, which contributed to her unwillingness to put her mother in a long-term care home.

> *I think it's a really sad, sad state to have to put anybody in. I was a friendly visitor last year. I went and visited some of the people from here that are now in nursing homes. And I thought, 'oh, my goodness'. Like, they were just so thrilled to see me walk in. And it's just so sad. So sad. And I just do not want that ever for my mom.* ~ **Sam.**

Caroline and Paul, who both provided care to their spouses, shared some insights from the time they spent working in long-term care.

> *They need more education on dementia and to learn how to deal with people with dementia. But it's not even just the people with dementia. They treat them [long term care residents] as objects. You know, when I had people come to me, they'd say that the staff toss them around like they are a bag of potatoes. These are people we are working with [voice breaking, tearing up]. And they do not pay the staff enough. If they paid them, they would have better workers. And if they give them full time jobs, instead of having them go part time at one place and another place.* ~ **Caroline.**

> *As part of my community nursing time, I've been in and out of these places for different patients that require IV therapy, wound care, or injections of medicines that their own staff were not allowed to give. So, I've seen the inside of lots of these places. Some of them are dark, dank, and just plain nasty.* ~ **Paul.**

Valerie and Nancy, who provided care for their mother-in-law and mother, respectively, shared stories they heard about long-term care homes in their communities, which made them hesitant.

> *We're limited [in long-term care options] with Alzheimer's, because you need lock and secure when she gets to that point where she wanders. If the home is not going to do that, we do not want her there because she'd be the person walking out, walking down the road. Because we just had a case of that at a long-term care home here, where a lady walked out at night, and she passed away from hypothermia.* ~ **Valerie.**

> *From what I've heard from other people who have had their family in long-term care home in this area, it's not a positive experience. From what I've heard, it's not staffed well. My father-in-law was in long-term care around here and it… they just did not treat him well. I do not want to leave her somewhere where she could be mistreated, and I'm not there. That thought stresses me a lot, to think about putting her in someone else's care who is not truly engaged in it the way that I am. Where it's more of a job and maybe a job that they are not even happy doing. And so, I feel like that could impact her care and her emotions. And I feel very protective of her around that.* ~ **Nancy.**

Due to their strong convictions most caregivers had about long-term care homes, they were motivated to continue aging in place despite the challenges they were facing, even if it was detrimental to their own well-being. Georgia, who provided care for her mother, stated as long as she was able to do so, she would provide care within the home:

> *This seems awful to say, but if something happens to me, well, then they are going to have to put her in a home for sure, because nobody else is going to do it. It's a lot of work, but I cannot not do it. But, you know, people say, 'well, you know, it would be better if she just went to long-term care'… might be better for who? Certainly not for her.* ~ **Georgia.**

Overall, the stigma surrounding long-term care homes and the overwhelming presence of negativity around the prospect of long-term care were overwhelming for caregivers as they tried to make appropriate care decisions for their loved ones with dementia. Bonnie, who provided care for her mother, shared that she initially had similar feelings about long-term care as other participants, until she had no other choice but to move her mother into a private long-term care, as her mother's care needs were more than she could handle alone. She shared how her thoughts were pleasantly altered after moving her mother to a long-term care home.

> *'Who wants to go into God's parking lot?' I have heard it worded like that. God's parking lot - long-term care homes. And that it's kind of like you are just waiting to die. But you know what? It's not. It's actually an engaged, enriched experience. Where there is comradery, there is kindness… you are in an environment where aging and all the different interventions that allow you to still have a beautiful life are happening.* ~ **Bonnie.**

This perspective was shared by other caregivers who had transitioned to long-term care. Bridget, who recently moved her husband to long-term care, shared how her relationship with her husband has improved since the move.

> *It's a different relationship. The community coordinator for our area, when he went into long term, said, 'now you can be his wife instead of his caregiver'. And I thought that put it really succinctly, because it's better. Because to be honest, I was getting a little bit resentful at the end, feeling very isolated. But truthfully, I have found it hard to switch my role.* ~ **Bridget.**

In terms of long-term care, Dana, who provided care for her parents and aunt with dementia, shared that she believed caregivers should consider long-term care early, in anticipation of their loved ones' increasing care needs.

> *I would say start with the long-term care options… it's better. It's better for everybody. I know, it's incredibly, incredibly emotional, but, you know, it's better for everybody. I think even with my parents, I'm sure I got more years out of them, because they were able to move then. If I had just, you know, left them in their home and tried to get some care provided for them in their home, they would not have lasted.* ~ **Dana.**

Dana further noted that considering long-term care placement early was important given the long waiting lists to get into long-term care. The reality was, if not considering long-term care early and deciding which homes were suitable for a loved one with dementia, the person living with dementia might be placed on a lengthy waiting list. Georgia explained this process for her:

> *We just put her on a list to get into a home. And they said it was a two year wait, and now it's doubled. Now, it's five years. So that was a year and a half ago. We put her on a list because we wanted to prepare for her decline, and she's five years until she gets into a home.* ~ **Georgia.**

Other participants shared they were often advised by friends and family to put their names on lists for long-term care as soon as possible due to the large waiting lists. Alternatively, persons living with dementia ran the risk of declining rapidly without increased care to match, or to be put on crisis placement until a bed became available, putting additional strain on the caregiver. Bonnie explained her thoughts on the long-term care situation in Canada by saying:

> *I think there's too many old people for the long-term care homes that exist. So, the big message is aging in place is a great thing to do…But I can tell*

> *you from my experience, my mom and her long-term care home, with her needs as severe as they are now versus aging in place, trying to put all the supports in place was too much. Her experience in long-term care was probably better. When it's at the point where it's that severe. When it's not that severe, then what should happen is the access to the supports need to be more seamless, more involved, and people need choice.* ~ **Bonnie.**

Overall, opinions concerning long-term care directly affected aging in place, as caregivers and persons living with dementia who had no interest in long-term care fought to stay at home as long as possible. Many caregivers cited personal experiences and conversations with others that contributed greatly to their negative perceptions of long-term care. Most caregivers shared in their loved one's fear of long-term care was similar to their own fears, with those who had decided to make the move to long-term care having mixed emotions. However, the issue of long wait times and a lack of available beds was also cited as a barrier to accessing long-term care when needed. Ultimately, the choice to place a loved one with dementia into long-term care or to continue aging in place was immensely difficult for caregivers, and the stigma and lack of availability of long-term care beds only exacerbated this challenging decision.

'The system is broken'.

Another area of concern for caregivers was the systems in place to support aging in place. The sentiment 'the system is broken' was articulated by caregivers throughout their interviews when referring to the health care system, with specific reference to dementia care. Caregivers' struggles with dementia care included their need to advocate constantly, issues with primary care physicians, challenges with home care providers (referred to by participants in this study and in Ontario contexts as personal support workers), and a lack of appropriate day programs/respite. Personal support workers, alternatively known as health care aides, refer to home care professionals who assists patients with tasks such as daily hygiene and medication management and provides respite for the caregiver (Zagrodney & Saks, 2017).

Caregivers shared the challenges and hardships experienced when trying to navigate the health care system and services put in place for aging adults, and specifically persons living with dementia. Caregivers shared their frustrations with care coordination, communication, personal support workers, and the available programming and supports. Many maintained that, along with their other caregiving responsibilities, they had to advocate to get the services required.

> *The only reason my mom got all the great things that she got is because I worked so hard to make them happen. They did not happen by themselves. The system is not set up to give people the help that they need.* ~ **Bonnie.**

Similarly, Caroline expressed frustration with the lack of coordination of care services (e.g. home care), which was an essential part of aging in place. This frustration was evident as Caroline became emotional not only for her situation but for persons who were not as able to advocate for their loved ones like she had.

> *It's hard to access services to stay home. I think that's the bottom line. I thought I knew how to navigate the system, and I'm fairly assertive. And it's difficult, it's very time consuming. Because the hours I have spent on the phone [long pause, voice breaking] trying to get him stuff. It's like, 'oh my God'. And I think of people who do not understand the system and aren't as assertive or have the problem-solving abilities that I have, and I'm frustrated. I can see why a lot cannot stay at home. The system is very difficult to navigate, just to even get home care. So, you know, the coordinator comes out. He qualifies for morning care seven days a week. I get excited. They cannot offer anything till 12/12:30 for morning care. He's not going to wait for a shower till then! And they tell me to call the case coordinator to tell them they cannot provide the services. Why do I have to call? Why aren't you calling them? And then, you know I'm the middle person. Excuse me? I should not be the middle person. And so, as a caregiver here, I am advocating for [person living with dementia] all the time. So, the system is broken, do not get me started.* ~ **Caroline.**

Along with caregiver advocacy, caregivers identified issues when communicating with primary care physicians regarding a dementia diagnosis. For example, participants needed to advocate for their loved ones before their formal diagnosis, as family doctors were not listening to their concerns and did not agree that dementia testing was necessary because the person living with dementia did not fit a typical idea of what dementia looked like. Valerie shared:

> *A huge barrier was getting her doctor to succumb to her having Alzheimer's. I never fought so hard with a doctor in all my life. I went over and above them to the Alzheimer's Society. And so that was a big hurdle for me... It made me most frustrated of anything I had to deal with… It was so difficult getting him on board. And it was like, 'oh, my God, you see her 15 minutes a day, maybe twice a year. Don't tell me what is going on in her life'. Even now with a formal diagnosis, he just downplays it all.* ~ **Valerie.**

Nancy argued the lack of communication resulted in her feeling like her mother 'fell through the cracks' in terms of the treatment she received from her family doctor following her diagnosis. Morrie also noted a lack of communication with the health care system affected his experience as a caregiver. He wished someone were more attentive in checking in on him and his care recipient for minor (or major) issues that arose.

> *If somebody were around more often, every month or two. Just to check in, it would be good. It does not need to be any more than a five-minute visit, probably. Like, you are having trouble with that? We can sort this out… It's just someone who could see that we are still here.* ~ **Morrie.**

Another concern expressed by caregivers was access and availability of home care and personal support workers. Caregivers' discussion of issues with personal support workers included too short of visits, missed visits, and a lack of adequate training. Bridget explained she felt she had no option but to constantly be around for her husband because the outside help was very limited.

> *I felt like I had no choice. I mean, you get help from outside, but as long as I was physically capable for the other hours, that was me. Because [outside help], it is twice a day, but basically it's maybe half an hour to shower like, even though they are assigned for an hour, there's travel time, etcetera. Eventually I got three hours respite a week. That's hardly any time at all.* ~ **Bridget.**

Further, Bonnie explained it was not uncommon for most personal support workers who looked after her mother to cut their visits short and not spend the full allotted time.

> *I remember this girl, she would spend the whole hour with my mom, and they would just talk about family, and they would look through photo albums and she'd spend the whole hour. She was literally the only one in the three years that my mom had that cared that much. Everybody else was in and out in 15 minutes. And I'm telling you, part of that is a scam, because they have to hit all the houses and then their work is done. So, if*

> *it's eight hours and they hit everybody in 15 minutes, then they are done. And I know that because it's a small town. So, I would go over to the grocery store, and I would see them doing their groceries in the middle of the day, and I'm like, but you were only at my mom's this morning for 15 minutes.* ~ **Bonnie.**

A lack of availability of personal support workers limited the respite caregivers received and further influenced the challenges felt in their roles. Paul shared similar experiences with personal support workers only staying for half the time they were meant to, along with his frustration with the number of missed personal support worker visits.

> *[Personal support workers] are lowly paid people. They're hard to find, a lot of the time. And it's not been uncommon for them to cancel a visit, because they do not have somebody to come. Luckily, so far, we have only missed one four-hour visit, in the summer months. But we lost a lot of single visits for one hour when she's supposed to take a shower.* ~ **Paul.**

Caregivers expressed concerns about personal support workers' lack of appropriate dementia training. Caroline and Paul shared their experiences with this:

> *I expressed my frustration with the [personal support workers] that they sent. And the communication within their program is ridiculous. I'm here, I speak to you, you say you are going to call to schedule and tell them all the things I told you. None of that happened. Just like, come on. And the guy comes, he does not know what he's doing. You get three tries, and then I call, and I said 'this isn't working. It's not a good match, and here's why. He's on the phone all the time, he doesn't listen to instructions'. I want to give them some insight as to what [Persons living with dementia] needs, who he is as a person. And what are some things that they can do during their four hours. When the guy comes and [person living with dementia] is here, I do not feel comfortable talking about his deficits in front of him. I tried to do it over the phone, but that did not work. And I give them some suggestions. You can play connect four. You can play this. I'll set up the WII for you. I said, I just do not want him sitting here watching TV for four hours. But did it work? No. So, I'm training the [personal support workers]. I said, 'send me somebody who works with dementia! Someone who has an understanding of dementia'. But if I wasn't this assertive, I get who I get.* ~ **Caroline.**

> *I would like to see training of the people they are sending. So, they have a better idea of how to deal with people, especially on days when they are going to come and spend four hours. They come and give quick showers, comb hair, dry it. Gone. They have no knowledge, in fact, it does not even say in their notes from what I've gathered, that she has dementia in the first place. It just talks about a fractured leg or something like that… They had supervisors who went out and visited with patients. They made a care plan. They would assign the staff that were going to come, whatever. We have not seen any supervisor from homecare…I do not even know if they send out supervisors.* ~ **Paul.**

In addition to the broken health care system, another area of concern expressed by caregivers was community programs. For example, participants expressed concern about the lack of dementia-specific programming for persons living with dementia and their caregivers. Most participants shared that the programs they would like to access were often not available or worth the trouble. When asked whether any programs had played a role in supporting her mother-in-law, Valerie shared:

> *The reality is … they have not played any role. And that's the sad part really. They have not because there's nothing really for them. And that's sad. I think how fortunate she is that she has us.* ~ **Valerie.**

Participants also shared issues with many programs in existence. Caroline explained she had issues with the dementia day programming her husband had accessed. She expressed that while some day programs were not too bad, not all were created equally.

> *The [name of city] program and the other programs we tried. They… They do not have programming… When [person living with dementia] calls me three times because he's bored. He says, 'we are done'. I say 'no, you just finished lunch, there's a program this afternoon'. And he says, 'well we are not doing anything'. So, they need to keep them engaged. But the staff that they have there… Sorry, but they would not be working for me if I was the boss. Or I would teach them how to work. I mean, they do one activity in the morning and one activity in the afternoon. And they do not do anything active. They do not do any exercise. And there's a lot you can do even when seated. You know, there's a lot of game stuff they could do too.* ~ **Caroline.**

Caroline also discussed how living rurally was a barrier to accessing programming for her husband, as it was about a 40-minute drive to the nearest town. Paul shared similar sentiments about rural community supports:

> *There are no community programs. [Paul's wife] would go [to a program] at one point in time for weekly meetings [when they lived in an urban area]. That lasted for a couple of hours. They played games. They sang songs. A little exercise. I'm not aware of any of those types of things in [rural area]. Which means we would have to get in a car and drive somewhere. And I'm not sure it's worth the effort.* ~ **Paul.**

Evidently, the lack of appropriate and suitable programming was a major pitfall to aging in place.

Overall, the sentiment 'the system is broken' was evident in all interviews. Caregivers expressed challenges with system navigation despite contending to be assertive and advocating for the person living with dementia. Caregivers further expressed issues with the diagnosis and treatment of dementia and the feelings of their loved ones falling through the cracks. Similarly, participants shared issues with personal support workers' lack of training and commitment. Programming for persons living with dementia and caregivers was effectively lacking, which ultimately affected persons living with dementia and caregivers negatively. Day programming was hard to access and poorly run, and thus, its benefits were not felt. Ultimately, many caregivers lack support and appropriate avenues for respite, which exacerbates the challenges of their roles. Issues in these domains created additional difficulties in aging in place and need to be addressed.

Discussion

Throughout the interviews, caregivers repeatedly discussed what was lacking in various aspects of the aging-in-place experiences. Interviews shed an important light on the major system failings experienced by caregivers and persons living with dementia alike. As it stands, the current system is not equipped to accurately address the needs of persons living with dementia, meaning caregivers oftentimes have no choice but to provide care regardless of how it impacts them. Caregivers in the current study expressed a lack of perceived choice regarding long-term care, a lack of appropriate home care service providers, and an overall lack of communication. These areas of concern demonstrate unmet needs for persons living with dementia and their caregivers, which threaten their ability to effectively age in place.

Lack of perceived choice in long-term care

Caregivers expressed mixed emotions about the perception of long-term care in Canada and how those opinions affected their ability to provide care. Caregivers who feared long-term care cited the avoidance of long-term care as a major motivator to continue to provide care within the home. They also emphasized a lack of choice in the matter, due to fear about long-term care being an unsafe option. The decision-making process about aging in place or long-term care placement for older adults in general was studied by Schierer et al. (2023). Their results demonstrated that indecisiveness was common during plans to continue to age in place or transition persons living with dementia to long-term care (Schierer et al., 2023). However, the study only addressed whether the decision to age in place changed rather than why it did or did not change; thus, the participants' reasoning for indecisiveness was not clear. More information about the reasons behind the indecisiveness would provide key insights into decision-making processes for persons living with dementia and caregivers.

In the current study, many caregivers had strong negative convictions about long-term care and increased their care demands for their loved ones to avoid placement. Negative perceptions of long-term care for persons living with dementia have been previously studied (i.e. Mullin et al., 2013) but deserve to be revisited due to the COVID-19 pandemic, which shed light on many negatives concerning long-term care in Canada (Steele et al., 2023). Further, there is a lack of existing literature addressing whether and how negative perceptions of long-term care might affect the care provided by caregivers while aging in place. In the current study, caregivers expressed that they pushed themselves harder to continue to provide care because the prospect of long-term care was inherently negative. All in all, caregivers and persons living with dementia deserve the opportunity to make an informed decision about care, rather than determining they must age in place due to the current long-term care landscape in Canada. It is imperative that families affected by dementia have a better understanding of the breadth of living arrangements (aging in place, long-term care, other options) for persons living with dementia so each family can make an informed decision that is most appropriate for their specific needs.

Lack of appropriate home service providers

Along with issues with long-term care, caregivers in the current study noted the lack of personal support workers available to provide home care for persons living with dementia. Caregivers noted the quality of care provided by the available personal support workers was disappointing. These claims are not uncommon, as previous literature has documented similar issues, demonstrating part of a larger systemic issue regarding the landscape of the treatment of personal support workers, personal support worker culture, and personal support worker practices. More specifically, personal support workers are often referred to as lower status within the health care field despite their large contributions to in-home care (Norris et al., 2024; Zagrodney & Saks, 2017). Personal support workers experience the lowest rate of pay of any health care worker in Canada (Hapsari et al., 2022; Norris et al., 2024) and experience substantial levels of work-related stress and burnout (Hignett et al., 2016). Personal support workers are undervalued and far too often face challenges related to precarious work environments, high turnover rates, exposure to physically demanding activities, abuse, insecure hours, and lack of continuity in care (Hignett et al., 2016; Jansen et al., 2009; Ward-Griffin et al., 2012). Further, there is a concern about a lack of supervision for personal support workers in particular, and the absence of bedside supervision by regulated professions, which has led to increases in occupational influences in which personal support workers alter or do not follow care practices, which ultimately affects the care recipient (Lopez, 2007). Personal support workers also lack opportunities to engage in additional skills training and education in general, let alone training specific to the frequently experienced challenges (Knopp-Sihota et al., 2023). Due to these factors and their resulting effect on the care environment, it is unfortunately all too common for care recipients to suffer as a result (Ward-Griffin et al., 2012).

It is apparent that a change needs to be made regarding the current landscape of home care, and personal support worker care needs to change in order to promote aging in place as a viable option for persons living with dementia. A study by Breen et al. (2021) explored personal support worker perspectives on the quality of home care in Canada for persons living with dementia. Personal support workers noted quality home care should be: (a) person-centered; (b) enhanced by personal support workers with dementia specifc training and education (c) informed by personal support worker specific experience and characteristics; (d) enhanced by accessible information from and care plan discussed with persons living with dementia and their caregivers; (e) inclusive; and (f) facilitated by organization supports and respectful care (Breen et al., 2021). Personal support workers also advocated for increased support through dementia-specific training, increased teamwork, quality staffing, increased exchange of client information, and increased wages. As Breen et al. (2021) only interviewed personal support workers regarding perceptions of quality home care, an undoubtedly important perspective on this issue is lacking, namely the perspectives of persons living with dementia and their caregivers. For example, participants in the current study emphasized that personal support worker care could be improved through enhanced communication with regulatory bodies such as supervisors, increased staffing, and better pay, all factors that might help to facilitate retention. Overall, issues with home care are systemic and perpetuated by the lack of appropriate support, education, and pay that personal support workers receive. Personal support workers play a critical role in aging in place care, and as such, they need to be in a position to provide quality home care for persons living with dementia.

Lack of communication

Another noteworthy issue within the current study was caregivers' frustrations regarding the lack of communication between health systems and services and caregivers. Caregivers expressed anger at a lack of continuity of care for their persons living with dementia. Caregivers recounted situations concerning their primary care physicians not following up with caregivers, significantly delaying their treatment, and being told they qualified for home care at a specific time, and learning later that care was not even available at the time needed. These situations resulted in caregivers having to play the middle person and spend countless hours of their limited time coordinating aspects of care. Given the progressive and changing nature of dementia, persons living with dementia are likely to encounter a variety of different health care sectors and require care from various providers throughout the disease trajectory (Clare et al., 2006). A lack of appropriate communication is evident between these systems, and serves as a major hindrance to aging in place and effective care for persons living with dementia. In the current study, dementia health care and social care services have been labelled as uncoordinated and difficult to navigate. There is great concern about the ability of the health care system to assess persons living with dementia, which directly affects their ability to maintain their quality of life (Manderson et al., 2012). Communication issues impede the ability of caregivers and persons living with dementia to successfully age in place and need to be addressed moving forward.

A bold but accurate solution to communication issues within and between health care services is the restructuring of the current health care systems' outdated methods of communication. The most recent Health Canada study assessing health care errors reported 25 per cent of health care professionals cited communication as a leading challenge (Baker & Norton, 2001). Despite Baker and Norton (2001) recommending a variety of solutions to these issues, nearly two decades later, the problem still persists. For persons living with dementia and caregivers, a more concrete and immediate solution is warranted.

One such solution to improve communication when navigating the health care system can be addressed by patient navigators. For persons living with dementia and their caregivers, patient navigation has been proposed as one model of integrated, family-centred care to support individuals during these processes. Patient navigation programs in the United States revolve around the premise persons living with dementia rely on a patient navigator to guide and support them through the health care system and improve access to services that meet their needs and promote integration of care (Freeman, 2013). Existing patient navigation programs in the United States provide information about supports (e.g. emotional), referrals to health and community resources, monitoring of diagnosis, treatment decision-making, and caregiver training, with some models including dementia specialists trained by clinicians (e.g. dementia-practice nurses) (Bernstein et al., 2020). A study by Kallmyer et al. (2023) explored care system navigation for persons living with dementia and provided guidelines on how this could be done more effectively. The researchers cited that the benefits of dementia care navigation were evident through increased self-reported quality of life and decreased burden (Kallmyer et al., 2023).

Despite these benefits, patient navigation programs are in the infancy stages in Canada, but substantial interest and investment are evident (Tang et al., 2021). A Canadian study by Tang et al. (2021) explored the role patient navigators have played in a hospital in Alberta, finding that certain patient sub-groups (e.g. individuals with cancer, pediatric patients, individuals with mental health concerns, individuals with substance use disorders) are well served by navigators. Issues with the programs assessed included a lack of awareness, recognition, integration, and geographic distribution (Tang et al., 2021). Overall, research on patient navigation programs is emerging, but is inherently slow in Canada. However, future research should assess their effectiveness for persons living with dementia in Canada, to better understand the experience of being and using care navigators.

Limitations

While the aim of the study was to recruit both caregivers and persons living with dementia to participate in interviews, persons living with dementia were not recruited to participate. Lack of recruitment of persons living with dementia may have occurred for several reasons. Some caregivers in the current study noted their loved ones with dementia were in the later stages of dementia and thus would not be able to actively participate in interviews. Further, other caregivers mentioned that the process (e.g. length of the consent form, background questionnaire) acted as a deterrent for participation. Regardless, there is no representation of the voices of persons living with dementia in the current study, except through the proxies of caregivers, a trend that exists in the current research landscape in general (Rios et al., 2016), but particularly for those in later stages of the disease. For example, Mazzei (2009) contends that the voices of persons living with dementia in early stages of the disease (e.g. most easily understood, friendly) are often highlighted within research, and less room is made for persons living with dementia in the later stages of the disease. As such, more work needs to be done to ensure a more holistic picture of dementia is painted by actively engaging persons living with dementia across all stages of the disease.

Another limitation worth noting is that most caregivers in this study were White, middle-class, and employed throughout their lives, and thus their experiences are not representative of all dementia caregivers. Further, there was also a lack of diversity in spousal caregiving in that all couples were heterosexual, and thus the experiences of this dynamic for same sex couples is lacking. Lastly, as four interviews were retrospective in nature (as these participants reflected on experiences within the last year), they may be limited by their recall of their experiences.

Conclusion

The experiences of caregivers in this study clearly demonstrate the critical role they play in the Canadian health care system. The need for reform in health care policies to address systemic issues and truly promote aging in place is warranted, as caregivers and persons living with dementia have and will continue to be underserved without meaningful change. Further, the need for increased funding, resources, and coordination of care would alleviate many stressors caregivers face and make aging in place a more viable option for years to come. The final note is that while recommendations outlined in the discussion *are* feasible, this is only the case if there is systematic change pertaining to policy and funding in this country. This requires a willingness to reassess current strategies/procedures and a recognition that persons living with dementia and their caregivers deserve choice, autonomy, and access to the best possible care at home and everywhere else.

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