

# Aging in Place: Challenges of Older Adults with Self-Reported Cognitive Decline



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## ABSTRACT

### Background

An emergent concern related to the aging and the increased risk of cognitive decline is the institutionalization of older adults. Evidence has shown that aging in place leads to many benefits, including higher quality of life. In order to support older adults, it is imperative that we understand the challenges people with changes in cognition face while aging in place.

### Methods

A total of sixteen older adults with self-reported cognitive decline and six informal caregivers of individuals reporting cognitive decline, all of whom are living in independent residences, participated. Focus group sessions with semi-structured interviews were conducted, followed by thematic qualitative data analyses.

### Results

Thematic analyses led to the identification of six challenges to aging in place, including: 1) memory decline, 2) emotional challenges/low mood, 3) social isolation/loneliness, 4) difficulty with mobility and physical tasks, 5) difficulties with activities of daily living/instrumental activities of daily living, and 6) lack of educational resources on cognitive change.

### Conclusion

The themes identified in the current study represent common challenges in aging in place for older adults with self-reported cognitive decline. Identification of these themes allows for important next steps, which can focus on supports through targeted interventions.

**Key words:** aging in place, cognitive decline, caregivers, focus groups

## INTRODUCTION

Approximately 1.1 million Canadians are directly or indirectly affected by dementia, a number that is expected to nearly double within the next 15 years.<sup>(1)</sup> A crucial concern related to aging and the increased risk of cognitive decline is the institutionalization of older adults, which has consequences for an individual's quality of life, for their family/caregivers, and for economic costs to society.<sup>(2)</sup> According to data from the Canadian census, the number of individuals who are able to age in place steeply declines with age, and cognitive decline including dementia was a strong predictor associated with transition to living in a long-term care home.<sup>(3)</sup> With increases in age-related neurodegenerative disorders, society must account for cognitive impairment as a growing challenge that is often unrecognized until formal diagnoses are provided, at which point a person may be less able to compensate at home.

Reports have indicated that 90% of individuals over age 65 years would prefer to age in place.<sup>(4)</sup> Aging in place is defined as “having the health and social supports and services you need to live safely and independently in your home or your community for as long as you wish and are able”.<sup>(5)</sup>

Research suggests aging in place evokes feelings of security and familiarity, as well as attachment and social connectedness, giving older adults a sense of identity, independence, and autonomy.<sup>(4)</sup> The preference to age in place is also strongly supported by empirical studies which have demonstrated that aging in place with cognitive decline, including dementia, can impact survival,<sup>(6)</sup> and personal and financial well-being,<sup>(7)</sup> compared to long-term care alternatives. In Canada, approximately 93% of individuals over age 65 years live in private residences.<sup>(8)</sup>

However, a consequence of the desire to age in place is an increased reliance on informal caregivers—family or friends who provide unpaid assistance with day-to-day tasks. Approximately 3.8 million Canadians over the age of 45

provide informal care to an adult over the age of 65; a quarter of these carers are older adults themselves.<sup>(9)</sup> Notably, over half of informal caregivers report challenges related to caring, such as it being emotionally demanding, time-consuming, and stressful.<sup>(9)</sup>

A fundamental part of helping individuals to stay at home safely for as long as possible is understanding the unique challenges that older adults with self-reported cognitive decline and their caregivers experience, so that such challenges can be addressed. Therefore, the goal of the current study was to identify the unique challenges of aging in place in Canada from the perspectives of older adults with self-reported cognitive decline and informal caregivers, all of whom were living in independent residences.

## METHODS

### Participant Recruitment

Older adults with subjective cognitive decline, mild cognitive impairment, or dementia, as well as informal caregivers, were recruited through the use of flyers posted in the community (at community centres and the University of Victoria-based Institute on Aging and Lifelong Health) and by word of mouth.

Eligible participants included adults aged 60 years or older who were self-reporting declines in their memory or other thinking skills, as well as informal caregivers of individuals reporting cognitive decline. Participants were required to be fluent in English and living in their own independent residence.

The current study was approved by the Human Research Ethics Board at that University of Victoria.

### Data Collection and Analysis

Data were collected via focus groups in order to encourage discussion among participants.<sup>(10,11)</sup> All participants engaged in one 90-minute focus group hosted either at the University of Victoria or at a local community centre between July 2018 and 2019 (a total of six focus groups were conducted). Upon arrival to the session, participants provided informed consent and then completed a short participant questionnaire which included questions about demographics, previous neurological diagnoses, cognitive, mood, physical concerns, living arrangements, and employment status. Subsequently, two investigators trained in conducting semi-structured interviews with attention to ethics and professional conduct facilitated the meeting. Interview questions were open-ended and aimed to identify challenges (i.e.: What kinds of activities have become more challenging at home? What have you found that you need more help with?), and potential solutions to aging in place (i.e.: What could help in your role as a care partner, with your health and well-being?) for older adults with cognitive decline from their perspective, as well as from the perspective of the informal caregivers. Each session was recorded and additional notes were also taken by a third investigator on site. All focus groups recordings were transcribed verbatim. Data were analyzed via thematic analysis for semantic (descriptive)

themes by investigators who had attended all of the focus group sessions and were familiar with the data. Verbatim transcriptions (which included non-verbal notations from the sessions, such as group members nodding) were coded line by line, and the main themes were identified, reviewed, named accordingly, and organized, along with the quotes discussed below (per the article by Braun & Clarke<sup>(12)</sup>).

## RESULTS

### Participants

A total of 22 individuals participated in the study, including 16 older adults with self-reported cognitive decline and 6 informal caregivers of individuals with reported cognitive decline. All focus groups consisted of a mix of older adults with cognitive decline and informal caregivers who were either spouses or adult children of an older adult with cognitive decline (average group size = four people). One caregiver also drew on professional experience as a home care employee. Notably, three older adults with self-reported cognitive decline had formal neurological diagnoses, including mild cognitive impairment, a history of traumatic brain injury, and Parkinson's disease. Participant demographics and characteristics collected from the participant questionnaire are described in Table 1.

### Main Themes

Six main themes emerged in response to the challenges with aging in place with cognitive decline from the perspective of older adults experiencing cognitive decline themselves (22 participants) and from the perspective of informal caregivers of older adults with cognitive decline (6 individuals). While our focus groups aimed to identify specific challenges of aging in place for older adults with self-reported cognitive decline, it is important to note that informal caregivers also expressed unique challenges themselves, which were inherently linked with difficulties of aging in place for older adults with cognitive decline. This information has been incorporated into the six main themes, outlined below.

#### 1. Memory Decline

Both older adults with self-reported cognitive decline and informal caregivers expressed that memory decline led to major challenges in aging in place in older adults' independent residences. The majority noted that the most common problem was forgetting items or difficulty remembering new information. One older adult noted, "I can't remember people names, I can't remember what I specifically did yesterday"—a comment to which others expressed agreement. In particular, remembering names and medications were the most frequently identified memory challenges for older adults.

Some older adults had implemented strategies, such as using cell phones and lists as reminders. However, more than one older adult in different groups identified that forgetting their cell phone at home as a common issue. Similarly, another older adult noted, "I always use lists. Sometimes I forget the

TABLE 1.  
Participant demographics and characteristics for individuals with personal experience of aging in place with cognitive decline and individuals with caregiver experience

|                           | <i>Individuals with Personal Experience with Cognitive Decline</i> | <i>Individuals with Caregiver Experience</i> |
|---------------------------|--|--|
| Females; Males            | 9;7  | 5;1  |
| Age (Mean±SD years)       | 80.16 ± 10.39  | 63.29 ± 17.35                                |
| Education (Mean±SD years) | 14.62 ± 3.20   | 15.20 ± 2.28                                 |
| Neurological Diagnoses    | 18.75%   | 0%   |
| Cognitive Concerns        | 100%   | 0%   |
| Mood Concerns             | 18.75%   | 40%  |
| Physical Concerns         | 61.53%   | 20.00%                                       |
| Living with family; Alone | 68.75%; 31.25%   | 83.34%; 16.66%                               |
| Retired; Employed         | 87.5%; 12.5%   | 50%; 50%                                     |

list though!” These instances have led to consequences such as, “I then accidentally buy the same groceries twice.”

**2. Emotional Challenges/Low Mood**

Both older adults with self-reported cognitive decline and informal caregivers explained that low mood is a particular challenge, especially since low mood is often associated with irritability when accepting help from others. For instance, one older adult stated that, “It’s depressing... I don’t feel I’m fine at times,” and another commented, “My self-esteem has suffered.”

Caregivers also reported concern about the reaction of the individual with cognitive impairment, which pertained to low mood and irritability. “She would react negatively, if I say ‘better let me do it’ that implies that she’s not capable, so I have to be awfully careful.”

Other informal caregivers expressed concern about their own low mood resulting from caregiver burnout, which sometimes conflicted with feelings that it would be “traumatic” to make a decision to have their spouse cared for by anyone else and that there would be greater “depression if separated from [their] partner.”

**3. Social Isolation/Loneliness**

Both older adults and informal caregivers expressed that older adults had difficulty connecting in their communities, which led to social isolation and loneliness. While it was broadly recognized that social support is of great value, the source of social isolation seemed to stem from multiple causes.

One was the loss of previous friend groups. For example, one older adult commented, “We had a large group of friends and we all did things together, but I can’t count on them anymore... they are all gone.” Many commented on friends who had “lost touch.” This seemed to relate, in part, to a perceived stigma of cognitive impairment and a need to hide it from others. For example, one informal caregiver commented that her parent was “isolated... possibly to avoid symptoms from being seen/realized by others.” Additionally,

older adults identified stigma attached to the experience of dementia, commenting, “Dear friends of mine could previously come over for tea. Dementia has a stigma and leads to their own fears of dementia.”

An additional challenge many expressed was a struggle of living alone and not having a means to form social connections. This often led to feelings of loneliness, with which participants expressed uncertainty around how to cope. Related to this, older adults and informal caregivers expressed concerns that there are not appropriate opportunities for individuals at different stages of cognitive impairment to become involved in community life. Older adults felt that information on opportunities to socially connect was not easily available, stating it is “hard to get information when you’re alone,” and that one “has to be proactive,” especially if not already part of a social support group that disperses such information.

Informal caregivers, themselves, also felt isolated and expressed a lack of time to connect with other caregivers.

**4. Difficulty with Mobility and Physical Tasks**

Difficulties with mobility and physical tasks were identified as key challenges in aging in place by both older adults with self-reported cognitive decline and informal caregivers. Specifically, safely completing household maintenance tasks as a result of mobility issues was an area of difficulty. One older adult stated that they “can’t get up on a step ladder anymore [to reach things] if a light bulb goes out.” Indeed, participants noted multiple concerns within this theme, including falls (e.g., when gardening, when navigating stairs), and opening medications and food packages (e.g., bottled water, milk caps) given the physical strength needed.

Older adults also expressed that in order to age in place, specific physical accommodations would be necessary for their home, such as wider hallways (e.g., to allow for walkers), and support rails (e.g., near the bath tub).

### **5. Difficulties with Activities of Daily Living/ Instrumental Activities of Daily Living**

There were challenges identified by older adults with self-reported cognitive decline and informal caregivers that all fell under the theme of activities of daily living (activities required to independently take care of oneself; e.g., toileting, bathing) and instrumental activities of daily living (cognitively demanding tasks required for independent living; e.g., cooking, cleaning). With regards to aging in an independent residence, there were two main areas of the home that were identified as particularly challenging: the bathroom and the kitchen.

The bathroom seemed to be a place where help was required, but where older adults with self-reported cognitive decline were less willing to ask, and the place where informal caregivers felt more uncomfortable providing support. Participants who identified these concerns seemed to be balancing safety and the need for privacy (e.g., when toileting or bathing).

Concerning the kitchen, numerous older adults made comments such as the following: “The kitchen is the hardest... just cooking in general.” When probed about why cooking had become more difficult, many identified safety concerns, such as “keeping the stove on.” Several participants across both groups acknowledged that this had been the key issue that led to an individual’s inactivity in the kitchen. Another difficulty in the kitchen was the clean-up required after cooking.

### **6. Lack of Educational Resources on Cognitive Change**

Both older adults with self-reported cognitive decline and informal caregivers expressed that a key challenge was a lack of resources/education regarding “normal” changes to expect with age. For example, both questioned, “How do you figure out what’s normal aging and what’s something else?” and “What are realistic expectations?” One older adult also stated, “We need a handbook on aging, but there’s no such thing.” Both noted that “it’s hard to get this information.” Relatedly, multiple older adults who had received in-home care noted that the individuals who came were not specifically trained to understand dementia and that the familial caregivers were expected to provide information, which became an additional challenge when a different provider would attend each appointment.

## **DISCUSSION**

The current study aimed to identify the unique challenges of aging in place for older adults with cognitive decline in Canada from the perspectives of older adults with self-reported cognitive decline and informal caregivers of individuals with reported cognitive decline. Thematic analyses of qualitative data led to the identification of six challenges with aging in place with cognitive decline, including 1) memory decline, 2) emotional challenges/low mood, 3) social isolation/loneliness, 4) difficulty with mobility and physical tasks,

5) difficulties with activities of daily living /instrumental activities of daily living, and 6) lack of educational resources on cognitive change.

Considering that eligibility for the older adults in current study included self-reported decline in cognitive functioning, the identification of memory decline as a theme was predictable and congruent with findings from the demographic survey. The emergence of this theme is central for the current study, given the aim of identifying challenges experienced by individuals with self-reported cognitive decline. Few studies have focused on this group specifically, and learning about the experiences of those aging in place with cognitive decline has been noted as an important topic to pursue in the literature.<sup>(2)</sup>

Across the other identified themes, several were consistent with previous research. Older adults with self-reported cognitive decline reported low mood related to the need for assistance and the associated decrease in self-esteem. Informal caregivers reported low mood as a result of challenges with providing care and experiencing burnout. Congruently, up to 20% of older adults in the community experience symptoms of depression, which is known to extend to and impact caregivers.<sup>(13)</sup> Indeed, caregiver burden is a significant problem and has been shown to affect more than a third of caregivers of individuals with mild cognitive impairment.<sup>(14)</sup> Notably, symptoms of depression have also been reported as a consequence of moving from independent residence into long-term care,<sup>(13)</sup> therefore, finding ways to alleviate mood symptoms while aging in place is a particularly important consideration.

Social connections have also previously been highlighted as an important factor for older adults aging in place.<sup>(15)</sup> However, the challenge of social isolation identified in the current study seemed to relate directly to issues pertaining to cognitive change. In particular, loss of previous friendships, partially due to the stigma of memory decline, was a key issue related to social isolation. In these cases, the identified issue of stigma also seemed to relate to the theme of lacking educational resources on cognitive change; previous friends did not seem to understand the cognitive decline and, as a result, no longer engaged in social activities with the affected person. Importantly, stigma has been associated with decreased quality of life and ability to age in place.<sup>(16)</sup>

Within the theme of difficulty with mobility and physical tasks, participants noted challenges pertaining to the structure of their home, such as navigating stairs. This challenge has also been noted by older adults in several other studies.<sup>(2,17)</sup> A number of participants reported that they had renovated their home or moved to a one-floor residence to cope or negate the physical mobility issues associated with stairs. Consistently, Safran-Northon<sup>(18)</sup> reported that home renovations such as this can improve prospects for aging in place among older adults. These themes of difficulties with activities of daily living/instrumental activities of daily living, as well as mobility and physical tasks, seem to be common challenges faced by diverse groups of older adults aging in place.

Similarly, difficulties with activities of daily living/instrumental activities of daily living were also a key challenge

identified, especially as they related to the bathroom and kitchen areas of the home, which were identified in the current study. Similar challenges were also noted by Faucett and colleagues,<sup>(19)</sup> based on structured interviews with older adults that were focused on home maintenance difficulties. Likewise, Kelly and colleagues<sup>(20)</sup> interviewed older adults and found common issues to those revealed in the current study around cooking and cleaning.

A final theme that emerged in the current study was the lack of educational resources about cognitive changes in older age. Participants explained that it is very difficult to understand the nuances between expected cognitive changes with age and early indicators of clinically significant cognitive decline (which may require intervention). Information seemed to be either totally missing or gathered from a variety of sources of questionable repute. Given that the participants in the current study had reported or were providing care for an individual with cognitive decline, this information may be particularly relevant for these demographics. Research has shown that providing informal caregivers with education contributes to relief from low mood and caregiver burden, and contributes to reductions in psychological and behavioural symptoms to those in their care.<sup>(21)</sup>

The current study focused on challenges in aging in place for individuals with cognitive decline. As a result, some of the themes, such as memory decline, difficulties with ADLs/iADLs, and lack of educational resources on cognitive change are likely specific to this group, and may not be expected to emerge as themes among older adults who do not self-identify as having cognitive decline. However, other themes, such as emotional challenges/low mood, social isolation/loneliness, and difficulty with mobility and physical tasks, may occur more broadly.

## CONCLUSIONS AND FUTURE DIRECTIONS

In terms of directions for future work, it will be important also to collect information from individuals who have been explicitly diagnosed with cognitive impairments (e.g., mild cognitive impairment). Indeed, a possible limitation of the current study is that all instances of cognitive decline in older participants were self-reported. Although several of these individuals reported being formally diagnosed with a neurological disorder, the majority had not undergone comprehensive neuropsychological assessment of their cognition and their cognitive decline was not formally diagnosed by a physician. It is possible that additional important and unique challenges could be identified from groups with specific dementia diagnoses (e.g., Alzheimer's disease). Notably, a study by Thoma-Lurken and colleagues<sup>(22)</sup> recently gathered qualitative data from groups of caregivers of individuals with dementia and revealed some similar themes including social network-related problems, safety-related problems (e.g., falls), and difficulties with activities of daily living. However, perspectives from individuals with dementia

were not included in that study.

Although it would be important to collect data from individuals with dementia, it is possible that recruitment will be an obstacle. Notably, recruitment for the current study proved to be particularly difficult given that the study sought older adults with cognitive decline that had challenges with aging in place, or from informal caregivers—individuals who were often overwhelmed/overburdened. The burden of participation was reduced somewhat by offering the focus groups in local community centres; however, this may remain a challenge for future work, particularly for individuals with established dementia.

The current study collected information from both older adults with self-reported cognitive decline and informal caregivers. Including both types of participants in the same focus groups allowed some dyads to attend the groups together, otherwise older adults with self-reported cognitive decline may have had difficulty navigating to the group independently and caregivers may not have been able to attend without securing care for their family member. However, it is possible that additional information could have been gleaned from interviewing each group separately, although this may have reduced the number of participants in the current study.

Considering the structural conditions that enabled the individual accounts in the current study, it seems that some of the concerns that emerged (e.g., mental health concerns, loneliness, lack of education on cognitive change) relate to lack of community supports and accessible resources. A lack of accessible resources also impacted other themes such as difficulty with activities of daily living, given the structure and barriers to home care. Moving forward, it will be important to consider how current policies and infrastructure can be improved. For example, interventions could involve changes to policy to decrease barriers and increase resources for mental health, education and physical supports, which should be made explicitly for older adults who are just starting to experience the impacts of memory loss, rather than depending on a formal diagnosis.

Ultimately, the goal of this research is to identify barriers related to aging in place, in order to be better equipped to proactively address these concerns and facilitate the transition for older adults and caregivers alike. Building upon the World Health Organization's definition of "age-friendly communities",<sup>(23)</sup> there has been increased interest, from both a political and policy lens, to identify features that make an environment more amenable to older adults, and especially to those with dementia. For instance, Menec and colleagues<sup>(24)</sup> have highlighted the need for federal aging-in-place policies that reflect current research on the environmental conditions that improve housing and in-home supports for older adults. By actually including older adults and their caregivers in these discussions, as was done in the current study, we can ensure that such federal policies will be attuned to the specific needs of the aging population in question. Identifying financially and practically feasible ways of addressing these challenges will also be an important step for future work in this area.

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## CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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