


# Dementia-Friendly Neighbourhoods in Canada: A Carer Perspective

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## RÉSUMÉ

Les résultats d'une étude portant sur les expériences de proches aidants de personnes atteintes de démence dans leur quartier ont permis d'envisager en quoi consisteraient des collectivités favorables aux adultes atteints de démence d'après la perspective de ces aidants, dans un contexte canadien. Douze proches aidants vivant à Ottawa ou dans les régions avoisinantes ont été interviewés en utilisant des cartes de réseaux sociaux, des entrevues mobiles et des photographies provenant des participants. Les résultats ont été organisés selon les catégories "relations", "lieux", et "pratiques quotidiennes". Ils révèlent que de nombreux choix des proches aidants concernant les entreprises fréquentées, les services, le lieu de résidence, les sorties et les pratiques quotidiennes sont fondés sur le désir de maintenir des liens sociaux et la citoyenneté sociale. En conclusion, des recommandations sont présentées en vue de la planification d'initiatives de quartiers adaptées aux personnes avec démences.

## ABSTRACT

Based on findings from a study examining the lived experiences of dementia carers in their neighbourhoods, this article offers a vision of what dementia-friendly communities could look like from a carer perspective and in a Canadian context. Twelve carers in Ottawa and its surrounding regions were interviewed using a combination of social network maps, mobile interviews, and participant-driven photography. The findings, organized according to the categories "relationships", "places", and "everyday practices", reveal that many of the carers' choices regarding businesses, services, home location, outings, and everyday practices, are based on a desire to maintain social connections and social citizenship. The article concludes with recommendations for consideration in the planning of dementia-friendly neighbourhood initiatives.

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*Well, we know [the neighbours] not personally, but every day...a lot of them go take a walk. A lot of people go around. They do the same thing that we do and they'll just wave and sometimes they'll stop, start talking. (Jack)<sup>1</sup>*

Jack, a 59-year-old carer to his wife with early onset dementia, made this statement in reference to his relationships with neighbours in the semi-rural Ontario town in which he lives. He went on to explain that his neighbours play a vital role in supporting him and his wife, by providing social contact, checking on his wife while he is at work, and generally “keeping watch” on them. Although Jack referred primarily to social relationships in this quote, the carers in the study on which this article is based – all caring for someone with dementia<sup>2</sup> – talked about the important role that numerous other aspects of their neighbourhoods play in shaping their daily lives as carers. They spoke of a multitude of factors in the built, natural, and social environment that determine whether they feel supported locally. This article aims to elucidate these factors, painting a portrait of what constitutes a “dementia-friendly community” from a carer perspective, in a Canadian context.

Based on findings from a study examining the lived experiences of dementia carers in their neighbourhoods, this article highlights the ways in which carers feel supported (or not) in their local environments, and puts forth concrete recommendations grounded in their experiences. The study, based in the city of Ottawa and surrounding regions, although not pretending to generalize to all Canadian contexts, nonetheless aims to offer a Canadian perspective on carers' experiences in their neighbourhoods, the combination of which has been lacking in the dementia-friendly literature to date. By focusing on carers' perspectives, the goal is not to dismiss the voices of those living with dementia, or to maintain a damaging trend whereby carers are often asked to speak on behalf of people with dementia. On the contrary, the goal is to consider the perspective of carers when it comes to imagining dementia-friendly communities. Although carers are regularly mentioned in the dementia-friendly literature as important allies or partners, there is very little empirical research examining this topic from their unique perspective. It is this gap that this article aims to fill.

I begin this article by providing a brief portrait of the dementia-friendly literature, with the aim of defining terms and situating Canadian initiatives within a global context. I then describe the research on which this article is based, focusing in particular on the various methods I used to build knowledge about carers' lived experiences of their neighbourhoods. I organize the findings into three main categories – relationships, places, and everyday practices – which help consolidate the carers'

stories and illustrate how carers' local environments can support their social citizenship. Finally, I conclude with recommendations for facilitating the integration of carer concerns and needs into dementia-friendly community planning.

I refer throughout this article to social citizenship, following Bartlett and O'Connor's (2010, p. 37) pioneering definition of the concept in the context of dementia: “Social citizenship can be defined as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible...” As I have also articulated elsewhere (Silverman, 2019), I extend Bartlett and O'Connor's social citizenship framework to include the carers of people with dementia, illustrating that they, too, are seeking what Bartlett and O'Connor (2010, pp. 39–48) identify as the foundational components of their framework; namely, opportunities for growth, the recognition of their, the carers', social position, a sense of purpose, participation in the world as social agents, solidarity with others, and freedom from discrimination. Although an increasing number of studies are addressing citizenship in the context of dementia (see, for example, Baldwin & Greason, 2016; Clarke & Bailey, 2016; Phinney, Kelson, Baumbusch, O'Connor, & Purves, 2016), Bartlett (2016) has articulated that social citizenship is a particularly relevant framework when considering the development of dementia-friendly communities, as “[the dementia-friendly community] initiative can...be seen as a struggle for citizenship in that it represents an attempt to change neighbourhoods, so that people with dementia are better understood, recognised and situated as equal citizens” (Bartlett, 2016, p. 457). Indeed, although this research did not initially set out to address social citizenship specifically, it quickly became clear, as I illustrate in the findings, that the carers' experiences in their local environments were deeply intertwined with what constitutes social citizenship as has been defined.

## **Dementia-Friendly Communities: Context and Literature**

This section provides an overview of the literature on dementia-friendly communities, showing that there is relatively little scientific literature regarding the outcomes and impacts of dementia-friendly community initiatives, and even less so in a Canadian context. Although some of this literature addresses carer concerns, more research is needed to understand what a dementia-friendly community would look like from a carer perspective.

Throughout the past 15 years, numerous terms have emerged to denote efforts to consider the needs of people with dementia, including “dementia-friendly”,

“dementia-capable”, “dementia positive”, and “dementia-inclusive” (Lin & Lewis, 2015; Public Health Agency of Canada, 2019). Numerous areas of daily life have been examined in order to make them more inclusive, including urban planning, interior design, and the accessibility of public, home, and long-term care spaces (Bartlett & Brannelly, 2019; Blackman et al., 2003; Hebert & Scales, 2017). Rather than address all areas of dementia-friendly indoor and outdoor design, this article focuses in particular on neighbourhoods and communities. I use the term “dementia-friendly” to refer to measures that support people with dementia and their carers and that aim to reduce stigma (Public Health Agency of Canada, 2019); in the context of neighbourhoods, such measures consider the built, social, and natural environment. Although the research on which this article is based was focused on carers’ experiences in their local environments or neighbourhoods, throughout this article I use the word “neighbourhood” more broadly than to refer simply to the defined boundaries of a geographic zone. As I will illustrate, in the current study, carers’ experiences of their neighbourhoods went beyond simply the local environment, and extended more broadly into their experiences of social and relational support both inside and outside the home, including long-distance friends and online support. In other words, the carers’ discussions about their neighbourhoods spoke to their broader experiences of community.

The majority of what is known, in the English language, about the need for, design, and implementation of dementia-friendly communities, has emerged from the United Kingdom, and more recently, other parts of Europe (Rothe, Kreutzner, & Gronemeyer, 2017), where pioneering initiatives began ahead of North America (Haggarty, 2013). This literature largely constitutes grey literature and/or policy documents that describe the theoretical and practical underpinnings of dementia-friendly communities (see, for example, Alzheimer’s Society & British Standards Institution, 2015; Bartholomew & Moore, 2014; Local Government Association, 2012; Mitchell, 2012; Public Health Agency of Canada, 2019). Similarly, the relatively small amount of scientific literature specific to dementia-friendly communities has also tended to focus on the elements that should constitute dementia-friendly initiatives, such as a project based in York, United Kingdom, that found that “everyday amenities such as banks, shops, transport and leisure facilities play a much more significant role” in the lives of people with dementia (Crampton & Eley, 2013, p. 52). Aside from a few exceptions (for example, Buckner, Mattocks, Rimmer, & Lafortune, 2018), there has been very little empirical research “testing” the outcomes of dementia-friendly community initiatives to determine whether they are effective in improving

quality of life. There has, however, been research examining various components that might be included in such initiatives; for example, Akhtar, Greenwood, Smith, and Richardson (2017), who found that “dementia cafés” were of great importance to the everyday lives of people with dementia and their carers, Brorsson, Öhman, Lundberg, Cutchin, and Nygård (2018), who analyzed how to make a grocery store both accessible and usable for people with dementia; Fleming, Bennett, Preece, and Phillipson (2017) who examined how the design of outdoor spaces and buildings can improve people with dementia’s experiences in their environments; and Ebert, Kulibert, and McFadden (2019), who found that when community members had person-based knowledge of dementia, it improved their social comfort with people with dementia, led to improved social interactions and reduced social isolation for people with dementia.

One of the largest English-language research projects on the topic of dementia-friendly communities has been the United Kingdom–Swedish project, “Our People, Our Places”, part of the Neighbourhoods and Dementia research programme funded by the Economic and Social Research Council and the National Institute for Health Research, and to which the current research initially had some links. This research team has brought forth numerous important findings to date in regard to both people with dementia and their carers, including the many ways that people with dementia are supported in their communities, from complex networks of relational support (Campbell et al., 2019), to the role of the social and natural environment in facilitating numerous aspects of everyday life (Odzakovic, Hellström, Ward, & Kullberg, 2018). Another of the many significant findings brought forward by this team is the reciprocity of neighbourly relationships for people with dementia and the fact that “neighbouring...forms part of the daily, often mundane activities of everyday life in ways that enable people to continue to maintain a degree of independence” (Ward et al., 2018, p. 7).

In Canada, the concept of dementia-friendly communities has been gaining traction, as evidenced, for example, in the recent national dementia strategy (Public Health Agency of Canada, 2019), which discusses the importance of the built and social environment in the support of people living with dementia. Pilot projects in various parts of the country, for example in British Columbia (Alzheimer Society of British Columbia, 2016) and Ontario (Webster, 2016), also attest to the desire to develop community initiatives specific to a Canadian context. Without necessarily being labelled “dementia-friendly”, there are examples of programming across the country, such as walking groups and art initiatives (Kelson, Phinney, & Lowry 2017; Phinney et al., 2016) that have aimed to “create

opportunities for people with dementia to participate more fully in the wider urban community” (Kelson et al., 2017, p. 10). It is not only in urban centres that such initiatives are occurring; there has also been concern for the specificities of supporting people with dementia in rural parts of the country (Bacsu et al., 2019; Wiersma & Denton, 2016). However, because there has been very little Canadian-based research to date regarding dementia-friendly communities, we do not yet know what might be unique to a Canadian context, as compared with other countries in the “Global North”. We know, for example, that rural communities, so common throughout Canada, have particular forms of social support (Wiersma & Denton, 2016). We might also imagine that the unique weather in Canada might contribute to particularities in terms of dementia-friendly communities, as well as our specific social policy context. Although the current research does not address all these concerns or hypotheses, it nonetheless offers a contribution to understanding Canadian dementia carers’ experiences of their environments.

Although some of the above-mentioned literature considers carers as important allies in the development of dementia-friendly initiatives, and some studies have even interviewed carers (Innes, Page, & Cutler, 2016; Mitchell & Burton, 2006), the perspective of carers has nonetheless remained on the sidelines of this literature. One exception is the United Kingdom-based study by Ward, Clark, and Hargreaves (2012), that examined how carers made use of their neighbourhoods both socially and physically, and how they were supported locally. These authors found that carers placed great importance on social contact as a means of maintaining their own identities and independence. Building on this important work, this article aims to expand on the topic of dementia-friendly communities from a carer perspective, in this case in a Canadian context.

### **Carers in their Neighbourhoods: Description of the Study**

This section aims to articulate the research methodology on which this article is based; namely, a 3-year-study that explored how dementia carers perceive, experience, and engage with the various aspects of their neighbourhoods. The research question asked: *What are the everyday experiences of place, space, and neighbourhood of co-residing carers of people with dementia?* The study investigated numerous aspects of the participants’ everyday lives: Where did they go? How were they getting to those places? With whom were they communicating? How were they being supported? These questions were intended to build knowledge about how carers use their neighbourhoods and how they are being supported locally. The project adhered to

Canadian Tri-Council guidelines (Canadian Institutes of Health Research, et al., 2010) and obtained ethics approval from the University of Ottawa.

Using a narrative methodological approach aimed at eliciting participants’ stories (Padgett, 2018), I employed three different data collection methods during three distinct interviews with each participant: social network mapping, walking interviews, and participant-driven photography. These visual and mobile data collection methods reflect current trends towards accessing the multi-sensory elements of a participant’s environment (Hurdley & Dicks, 2011; Pink, 2015; Ward & Campbell, 2013). These methods were an excellent match for the current project in which I was building understanding about numerous dimensions of carers’ experiences in their environments. Indeed, as I will explain, this combination of methods allowed me to gain a multi-faceted understanding of carers’ lived experiences.

I recruited participants through a community-based organization specializing in programs for people with dementia and their carers, servicing the city of Ottawa and its surrounding regions. Following a presentation to practitioners at both the urban and rural sites of this community organization, I asked practitioners to distribute recruitment posters as well as to identify any potential carers who they deemed might be a good fit for the project. Interested carers then contacted me directly for further information. Although eliciting the help of practitioners made the recruitment process relatively efficient, it led to a large limitation; namely, that it excluded more isolated and marginalized carers who were not accessing services. It is only recently, as I have begun delving into research that combines older age with other forms of marginalization, that I realize the extent to which the flaws in my research design – namely, (1) not reaching out to a diversity of carers, and (2) not asking sufficient questions related to identity and social position – stem directly from my position of privilege. As I mention further in the discussion section, people’s experiences of place and space cannot be separated from the multiple aspects of their identity.

Of the 12 carers recruited, 8 identified as women and 4 identified as men. Eight participants were caring for a partner, and four were caring for a parent. The carers ranged in age from 52 to 81 years old, and the partners and parents for whom they were caring ranged from 59 to 90 years old. These partners and parents represented a range of stages of dementia, from early to late. All participants were currently living at home with the person for whom they were caring, although one participant’s wife entered a long-term care facility during the course of the research. These dyads were living in

diverse environments: four were living in semi-rural areas, three in urban areas, and five in suburban areas.<sup>3</sup>

I explained to participants that I was seeking to build a portrait of their daily lives in their environment, including where they went and why, with whom they interacted regularly and why, and how they felt about their environment. All the interviews took place in the participants' homes or surrounding environments, and this proximity provided additional information about their daily experiences. During the first interview, I asked participants to create a social network map, a document that illustrated with whom they communicate and interact on a regular basis, whether friends, family, neighbours, service providers, or others in their community. This technique is described in detail by Campbell et al. (2019), a team that also conducted social network mapping with carers of people with dementia. As described by Campbell et al. (2019), the maps "encourage participants to reflect and consider their relationships over time and how they structure their social lives, encouraging them to depict these relationships on paper" (p. 10). Creating these maps elicited discussions about the participant's connections, and how these connections are linked to everyday practices (Emmel, 2008; Emmel & Clark, 2009), in this case in the context of care.

During the second interview, typically scheduled a few weeks after the first, I conducted a walking interview in the participant's neighbourhood. For three participants with reduced mobility, I instead conducted a driving interview. These mobile interviews ranged in length from 15 to 90 minutes, with the route determined by the participant. I asked participants to take me on a walk in their neighbourhood, on a route of their choice. Some participants chose to take me to a particular destination that they wanted me to see (e.g., the local general store), whereas others took me on a route representative of a typical leisure walk. I followed alongside with a microphone as they showed me their neighbourhood and discussed their local environment, which ranged from busy urban streets to quiet countryside paths. I audio recorded these interviews, as well as taking photographs of important landmarks in order to have a visual memory aid when reading the transcripts. As we walked, I asked questions such as "Can you explain to me where we are right now?" These questions elicited discussion about the participant's thoughts and feelings regarding various aspects of the local environment, including comments about neighbours and other social relationships. The mobile interviews provided a portrait of the local, dynamic environments of participants (Carpiano, 2009), including their built, natural, and social aspects. A detailed explanation of walking interviews with people with dementia has been written by Odzakovic et al. (2018),

and many of the techniques described were used in the context of the current research with dementia carers.

During the third and final interview, I conducted a photo-elicitation interview, using photographs taken by participants. At the end of the first interview, I loaned each participant a camera and asked that person to take approximately 12–15 photographs of meaningful places, spaces, or objects. I purposefully gave broad instructions, in order to encourage participants' own interpretations about meaningful aspects of their environment. The photographs, which included diverse images such as walking trails, benches, Christmas lights, cars, mailboxes, coffee shops, general stores, and household objects, acted as elicitation devices (Clark-Ibanez, 2004; Harper, 2002), stimulating discussion about participants' everyday life and practices. Sitting next to participants as we looked at each photograph together on my laptop, I asked them to explain why they took that particular photograph and what was important to them about those images. Similar to the social network maps and walks, these questions brought forth reflections about what participants felt was meaningful in their daily lives, and also helped situate participants in their local environment.

In addition to the data collection methods described, I also wrote extensive field notes after each interview as a way of facilitating a self-reflexive stance and assisting in my overall understanding of the material. As a result, there were multiple layers of data to analyse, including transcripts, network maps, photographs, and field notes. I coded the photographs and transcripts from all three types of interviews, and used my field notes as an additional source of insight, as they contained notes about my impressions of the sensory environment that are not captured in the transcripts (sights, smells, feelings). Despite the challenge of organizing this dense data, the advantage is that it led to a triangulation of data that contributed to the trustworthiness of the findings (Padgett, 2018). Using the software NVivo to help organize the data, I winnowed the raw and partially processed data into initial meaning units or codes, and then developed these codes into preliminary concepts and finally into principal themes (Padgett, 2018).

### **Relationships, Places, and Everyday Practices: Findings from the Study**

This section articulates the main themes that emerged from the interviews with participants. The carers in the study discussed numerous aspects of their everyday lives, including social interactions, experiences in the built and natural environment, and the businesses and services they used. The themes that emerged from their stories all referred to the people in their lives, the places where they went, or their everyday routines. Therefore,

for the purposes of organizing this article, I have grouped the findings into three main categories: relationships, places, and everyday practices. Together they elucidate how carers interact with their local environment, how they are being supported, with whom they are interacting, and what places they consider important. However, it should be noted that these categories are not discrete, but rather interdependent. For example, as will be discussed, the choices that participants made in terms of where to do their shopping were influenced by both relationship-based and place-based considerations.

### Relationships

Carers' connections with others, whether family, friends, acquaintances, business clerks, service providers, neighbours, or strangers, shaped, and were in turn shaped by, the places and everyday practices that were central to the carers' lives.

### Family and friends

The carers explained that although certain familial and social networks shrank following the dementia diagnosis, others expanded, and new ones were created. Sylvia, a 66-year-old carer to her husband, stated: *"Sometimes it's surprising who is supportive and who isn't."* She went on to explain that, to her disappointment, certain friends and family members whom she anticipated would be supportive, had withdrawn. This sentiment was also expressed in part by Andrew, a 71-year-old carer to his wife, who stated: *"It's the ones that were [her] friends, especially her co-workers that have drifted away – not in any bad sense, but in the sense that it's just very difficult for them to see her and to see the way she is."* Participants reported that family and friends often did not know how to help, and had difficulty managing their own difficult emotions such as sadness or discomfort. As a result, the carers' usual networks of support became more restrictive.

Yet despite the withdrawal of some friends and family, participants talked about obtaining support from unexpected new sources, such as people they met in support groups, or people formerly on the periphery of their lives such as hairdressers, business clerks, or contractors. Furthermore, many carers talked about sources of support that extended far beyond a local context; for example, exchanges with long-distance friends. Although Andrew witnessed the withdrawal of some of his wife's friends, he simultaneously became closer to other friends, in this case a couple who lived on the other side of the country: *"Interestingly enough, they've become even closer friends now through the internet and email and we exchange much more frequently and much more intimately than we did when they lived here. I couldn't have*

*expected it."* Statements such as Andrew's illustrate that carers are being supported not only locally but by a larger network of community.

### Neighbours and strangers

Carers also reported both positive and negative experiences in regard to their interactions with neighbours and strangers. With regard to neighbours, Doug, a 63-year-old carer to his wife with early-onset dementia, who had moved recently to Ottawa from another part of the province, stated that neighbours played no role in supporting his caregiving: *"Well, the neighbours are nice. They're friendly enough, but they're not friends. So we don't invite each other to each other's houses, type of thing. We meet on the street, say hello, but it doesn't go much further than that."* This contrasts with the reality of Jack, a 59-year-old carer for his wife, who relied heavily on the helpful neighbours in his small town: *"They're very nice. They're always asking if there are any problems. They keep an eye and they keep reporting to me too."* Other participants echoed this sentiment, saying that neighbours provided an extra set of eyes and ears (for example in situations of wandering), helped with small tasks such as taking out the garbage, and were at times an important source of social connection. Neighbours were also seen as sources of latent support, meaning that the participants took comfort in knowing they could call upon a neighbour if needed.

Some participants explained that they were confronted with stigma on a regular basis, sometimes in their interactions with strangers and acquaintances. For example, Maureen, a 54-year-old carer to her mother with late-stage dementia, explained that her mother's propensity for hugging strangers on the street or in stores sometimes elicited strong negative reactions. Maureen explained that she was always trying to gauge the reactions of others, because, as she stated, *"I don't want to offend anyone or have them feel uncomfortable."* She went on to explain that *"there are some people who are, whoa, one is quite expletive to Mom, [saying]... 'F-off, I don't know you!'"* Although Maureen did not use the word "stigma" to describe this type of violent reaction, it is clear that she was regularly anticipating and managing the negative perceptions of others. Other participants used the word "stigma" directly, referring to subtle examples in everyday life in which they and the person for whom they are caring have to manage negative reactions. In the following quote, Sylvia talked about the relief she felt when speaking to an acquaintance with an understanding and welcoming reaction, rather than a stigmatizing one: *"You know she's a very good listener, but her grandmother had had dementia so she can also make certain comments...and I think with her you get no, none of this stigma at all."*

Stigma was by no means pervasive in all the participants' experiences with strangers; many reported positive interactions. For example, for many participants, often just a wave to someone on the street was enough to help them feel less isolated. Furthermore, many participants mentioned that one facilitating element for making contact with strangers was dogs. Barbara, a 66-year-old carer to her husband, explained that dogs offered an entry point into social contact and a good excuse to talk to someone: *"I walk and then I meet the dogs, some that are at home and some that wave to me through the window... And then they will come and I will say, it's okay, that dog knows me. So I've met people walking their dogs."*

Whereas it might be awkward to talk to a stranger who is walking down the street or sitting in a park without a dog, the animal justifies hellos, waves, smiles, and comments, helping carers feel less alone.

#### *Businesses and services*

I categorized businesses and services under the heading "people" instead of "places", because the overwhelming majority of carers in the study explained that their choice of stores, whether grocery stores, pharmacies, banks, or hairdressers, was based largely on social relationships and social connections. The carers in the study wanted to shop, especially when with the person with dementia, in stores that had a welcoming environment created by workers who were understanding and helpful. Maureen, who found it challenging to bring her mother shopping because of her habit of hugging strangers in stores, stated: *"Well, the grocery store we tend to stick to the one store because they know Mom, but occasionally we'll go to the others."* This was echoed by Jack, who made the following comment about his local general store: *"I go in there and check mail and whatnot and they're always speaking to her when she comes in. They'll make us feel comfortable."* For some, this familiarity and comfort was the result of a long-standing history with the business owners; for others, it was a comfort created from the welcoming and accepting nature of the staff.

In addition to seeking out stores with welcoming and non-stigmatizing environments, carers also explained that they sought out stores that were conveniently located and accessible in terms of layout, lighting, and sound. When shopping with the person with dementia, they sought an environment that was familiar (for ease of finding products), not too bright, and not too loud. These considerations are similar to what Brorsson et al. (2018) discovered regarding the accessibility of grocery stores for people with dementia; namely, that people with dementia were seeking stores that were not only accessible but easily usable. In this sense, people with dementia, and carers who are supporting people with

dementia, are seeking similar elements in their shopping experiences.

For some carers, shopping also meant seeking out stores in which they knew they would run into people and have a chat. Tina, a 72-year-old carer to her husband, explained that she enjoyed running into neighbours and acquaintances while shopping: *"The post office – there are a couple of ladies who are there for quite a while. I talk to them a little bit, but it's small talk really. And I go to Shoppers. I know a few ladies in there – you just say how and how are you and, like I said, small talk."*

Tina's statements reflect the extent to which social connections play a large role in determining carers' choices of businesses and services.

#### *Places*

As illustrated throughout the findings, places are not removed from relationships. In fact, relationships and connection were the driving force behind carers' decisions about where to live and where to spend their time.

#### *Home*

The feelings that carers expressed about their homes were directly linked to their feelings about the neighbourhood in which their home was situated, and in particular, their experience of social relationships in that neighbourhood. In other words, the quality of those relationships was primarily what shaped participants' perceptions about the emplacement of their home. The length of time participants had been living in their homes did not seem to have an impact on the quality of neighbourly relationships. Jack, who had moved a few years previously to a small town, expressed: *"But like I say, people around here – I think it's the best thing I've ever done, deciding to move down here, preparing for our retirement."* Jack was in a financially precarious position and had to work night shifts at a local store in order to make ends meet. A few times a week his next door neighbour came to check on his wife while he was working his night shift. In Jack's case, financial precarity led him to rely more heavily on neighbours in order to ensure his wife's safety while she was home alone.

In contrast, Iris, an 81-year-old carer to her husband, was not able to benefit from local support, and this led her to experience feelings of ambivalence about where her home was situated. However, she traveled with her husband every summer to a different region a few hours away, and in this other location she had a completely different experience: *"The summers are wonderful because we're on – talk about a dementia-friendly road. My family's been going to this place for five generations and... everybody on the road knows [my husband]... They've had experience about Alzheimer's in their family and so it's wonderful. It's a*

*little road...if he goes over and visits, they clear it with me, can I offer him a glass of wine, should I give him a coffee?"*

The foregoing examples highlight the ways in which numerous aspects of the local environment, both structural and social, can have a direct impact on social isolation, and provide food for thought regarding growing dialogue on these topics in Canada (Weldrick & Grenier, 2018).

### *Community gathering places*

The carers in the study also talked about the importance of accessible, public, community places such as coffee shops, libraries, or community centres. They explained that these places supported social connections, helped break isolation, and maintained the relationship with the person with dementia by offering a place to go and an activity to do together. Many carers mentioned the importance of Tim Hortons, the iconic Canadian café, whereas others talked about the local library, the restaurant where they had breakfast each week, or the general store in the village that also acted as a post office and café. These places were vital to the everyday lives of the carers, as they were places grounded in routine, where they were "regulars" and where they had established a familiarity and a history. These places offered a destination for outings with the person with dementia, and a place where they could both be "out in the world" together and interacting with others, in a welcoming environment.

Community gathering places facilitated opportunities for both the carer and the person with dementia to exercise their social citizenship, as they helped fulfill many of the fundamental tenants of social citizenship as described in the introduction, namely having a sense of purpose, experiencing solidarity with others, participating in the world, and enjoying freedom from discrimination (Bartlett & O'Connor, 2010). For example, Jack explained that he took his wife to the same local restaurant for breakfast every week and that this was an important opportunity for exercising social connections and solidarity in an environment free from discrimination: *"Every Tuesday morning we go for breakfast...and she enjoys that – people around us that know her and to get to talk and everything."* Similarly, Tina commented about the Tim Hortons where she went regularly with her husband and where they both felt that they were participating in the world: *"See, this is Tim Hortons where I'm maybe going to bring him. That makes his day."*

Some carers explained that community gathering places did not always have to be indoors, but could also be an outdoor open space, such as a public square with benches that facilitated contact with others. Barbara

explained that the benches in the local square were a neighbourhood meeting location that facilitated solidarity and connections: *"Yes it is a social bench...If I want to be alone, they respect that...But then sometimes you talk and then they start and I say – okay, I'll go and sit and listen because I realize that some people have nobody to talk to."*

These examples illustrate that, as with the choice of businesses and services, the social connections that occurred in these community gathering places were of primary importance. This finding parallels what Ward et al. (2012) also discovered when talking to carers about cafés and other neighbourhood meeting points: that they facilitated vital social connections.

### *Favourite places*

In addition to explaining the importance of community gathering places in their everyday lives, many carers in the study talked about having a favourite place. Contrary to community gathering places where they would most often go with the person with dementia, favourite places were places where they would usually go alone and which would offer them a temporary reprieve or a sense of restoration in the midst of the challenges of their daily care routines (for more detail about the restorative aspects of favourite places, see Silverman, 2018). Often these places were not far from home, sometimes even in the backyard or the garden. For example, in the following quote, Barbara talked about the peaceful aspects of her garden: *"This is my back yard...I'm a nature person and just to have a back yard like this where there's nobody and there's squirrels all the time and nuts galore...It's wonderful and I wanted to say that I look out here and it's peaceful. I enjoy that very much so it's important to me to have nature around."*

Sometimes carers' favourite places were located in the natural environment, such as Barbara's garden, yet some carers also experienced a sense of restoration through the built environment, such as Albert, who enjoyed looking at the architectural design of local buildings, or Tina, who purposefully shopped at a certain mall because she liked to sit at a specific bench and look up at a pattern of lights that she found peaceful. Whether inside or outside the home, whether in the natural or the built environment, favourite places tended to facilitate relaxation, restoration, and even respite for many carers in the study.

### *Everyday Practices*

The people and places in the local environment also played a significant role in carers' everyday practices, both in terms of their caring role, as well as their own self-care.



### Daily routines

The carers in the study spoke at length about their care tasks and routines, and it was clear that for many, the local environment played a supporting role in shaping and facilitating those routines. In the following quote, Jack explained some of the main elements of his routine with his wife: *“So I get up in the morning – breakfast – fix her breakfast. Then we do a little bit of cleaning, you know – she helps me out. Or if we have to do any washing, we do the washing at night. But no, during the day we go out and take a walk together and come back. We do different days, different activities. Mondays – we started on Mondays about six weeks or so ago – I started to bring her to the bingo.”*

The natural environment thus played a role in Jack's routines, as he went on a daily walk with his wife (see more on walks subsequently); the built and social environments also played a role as he and his wife attended a weekly bingo game in a local community centre.

It was not only the carers' routines with the person with dementia that were shaped by the local environment, but the carers' self-care routines as well. For example, Deborah, a 54-year-old carer to her mother, discussed the importance of her daily walks, alone, in her neighbourhood, in order to clear her mind and get regular exercise: *“I make sure that I get out every day to get some exercise in.”* Similarly, Sylvia attended a regular aqua-fit class at the local pool: *“most weekday mornings I try and go to aqua-fit for 8:30. I like the people there. It's good exercise for me and it just, for me, starts the day off right.”* In this case, Sylvia's self-care routines were supported by a local facility, including the social connections that she fostered there.

### Walks

As I discuss in detail in another article (see Silverman, 2019), walks, both alone and with the person with dementia, emerged in this research as a vital component of carers' daily routines. The carers explained that walks served different functions at different moments, depending on the circumstances. In particular, walks facilitated connections with the person with dementia, with the social environment, with the natural environment, and with the self. For example, for Barbara, going on a walk reminded her of all the people she knew who lived close by, and this gave her a sense of comfort: *“And then I just realize that I know so many people.”* For Maureen, walks were moments to spend with her mother, to decompress and to do an activity together: *“Well, this route is our leisure walk when we know we have time in our day to spare, to go and enjoy the weather or just the fresh air. Depending on the day, the weather isn't the matter. We'll dress for the weather, even with the umbrellas and stuff. And yes, so this one's a nice little route and it's a whole series of right turns.”*

Maureen went on to explain that in addition to providing an opportunity to connect with her mother, walks also offered a release of tension at moments when her mother might be experiencing high stress or distress. For others, walks facilitated social connections, in some of the ways that I have described; for example, smiling or waving at people, saying hello to dog owners, or seeing school children getting on or off the school bus. Furthermore, many carers expressed that simply the fact of being out in the world, of seeing others and being seen, validated their sense of self beyond their carer role and helped maintain their sense of social citizenship (Silverman, 2019).

### Weather

This research was conducted in a part of Canada in which there is a significant amount of snow and other challenging weather for half of the year. I was, therefore, curious to understand the impact of weather on carers' daily routines, patterns, and choices. The majority of carers expressed that although bad weather made outings more difficult, they still made efforts to go out regularly, even if those outings were fewer or shorter. For example, many carers expressed that although bad weather might shorten or change the destination of a walk, it did not stop them from walking. In the following quote, Barbara explained her strategy when there is ice on the roads: *“I wear my studs or something and I just go and be just careful, but I'm aware of it. Oh, I have to be out. I walk every day.”* It should be noted that the majority of the carers in the study had a high level of physical mobility. For those carers with reduced mobility, walking was replaced with other outings, such as drives, and for them bad weather had the same impact: it might shorten the outing or change the destination, but it did not stop them from going out altogether. It is also important to note that the findings would likely have been different with carers living in very rural settings. The participants in the current study were all living in areas with snow plowing and road maintenance service.

## Where Do We Go from Here? Discussion and Recommendations

The findings reflect what is known thus far regarding some of the important elements of dementia-friendly communities, and extend these elements to carers. For example, the findings confirm that, similarly to how the accessibility and usability of grocery stores and other shops are important to people with dementia (Brorsson et al., 2018), they are also important for carers. In addition to the accessibility and usability of the built environment of such stores, the social and relational environment is also important for carers. Additionally, the findings validate that public gathering places, such as cafés, are not

only vital to the lives of people with dementia but to their carers as well (Akhtar et al., 2017), reinforcing the supportive role that neighbours and strangers play in the lives of many carers. Additionally, the carers' frequent mention of the role of animals, especially dogs, in maintaining their social connections, adds to the growing conversation about the links between pets and social participation in the lives of older adults (Toohey, Hewson, Adams, & Rock, 2018). The fact that there are many areas of overlap with other dementia-friendly projects from other countries indicates that Canadian dementia carers may have many of the same concerns and needs as carers in other countries in the "Global North". However, it would be important to explore carers' particular needs in different parts of Canada, especially in rural, Indigenous, and Northern communities.

Perhaps the most important finding is the fact that carers, like people with dementia, are seeking to reinforce and maintain their sense of social citizenship. They are actively exercising this citizenship through everyday routines such as walks, shopping, or going to a favourite place. This confirms that dementia-friendly neighbourhoods can, indeed, provide a forum for the application of a social citizenship model of dementia (Bartlett, 2016). Carers want to remain connected to their social networks and community, as is evidenced through their routines and practices, such as going to stores where they will run into people, bringing their partner or parent to cafés where they will be welcomed, or waving to strangers while on a walk. They are seeking connections and support, whether in their local environment with neighbours or farther afield with long-distance friends. The built and natural environments play a role in facilitating these social connections.

As mentioned earlier, one of the limitations of the study was the fact that it did not address the impact of various forms of marginalization on people's experiences of place and space. People who face stigmatization and discrimination because of marginalized identities, whether it be people belonging to racialized communities, linguistic minority communities, those identifying as LGBTQ, or those having different forms of disability, will necessarily experience their environments differently. For example, how do carers interact with neighbours when there are linguistic barriers? Do carers who are trans or non-binary avoid certain stores where they have been mis-gendered? Do racialized carers avoid certain streets for fear of their safety? These examples probe more broadly into questions about who is entitled to take up public space, who is invisible in public space, and who is targeted in public space. Future research is needed on these topics in order to create dementia-friendly neighbourhoods that are safe and inclusive for everyone, and in which people with dementia and their carers are supported instead of further stigmatized and

marginalized. Without this work, any portrait of dementia-friendly neighbourhoods remains incomplete.

With these limitations in mind, we can nonetheless ask the question, what would a dementia-friendly neighbourhood look like from a carer perspective? The following are concrete suggestions, emerging directly from the findings, which could be included in the shaping of future dementia-friendly neighbourhood strategies:

- Businesses should strive to offer people with dementia and their carers a welcoming, helpful, usable, and accessible built and social environment.
- Community gathering places, such as cafés, libraries, general stores, and community centres, should be maintained and more should be created if needed. The value of such places in facilitating social connections should be recognized and their role in communities should be upheld. The design of outdoor spaces should also reflect the goal of facilitating social connections. This could be achieved in part through the design of public squares and meeting points, or benches in strategic locations.
- Carers and people with dementia should be supported in their walking activities. Elements that support walking include having sidewalks on most streets, plowing and salting sidewalks in winter, and maintaining small "destinations" in each neighbourhood, for example community mailboxes, cafés, parks, or public squares.
- Carers should be supported in seeking out their favourite places as regularly as possible, in the hope that they can help facilitate a sense of restoration. For some carers, this can be accomplished while in the midst of everyday routines; for others, getting to a favourite place means relying on the assistance of others or on respite services, which should be made more plentiful and accessible.
- Communities should find ways to exploit the advantages of dogs as potentially helpful social connectors. This might take the form of informal community-based activities involving dogs, so that people with dementia and their carers can have access to these animals (and their owners) if desired.
- Discussions should be had about how to mitigate the negative impacts of bad weather, in order to support the efforts of people with dementia and their carers to be active even during the winter months. This is an especially important consideration in Canada and one that warrants further research, including the fact that some older Canadians leave the country during the winter, potentially reducing sources of support for people with dementia and their carers.
- The vital work of reducing the stigma related to dementia must continue, as this has a direct impact on people's experiences in their neighbourhoods and communities. When imagining what dementia-friendly neighbourhoods should look like, we must keep in mind that people's experiences are potentially shaped by multiple forms of discrimination. There is also a need for ongoing sensitization, knowledge building, and activism regarding people with dementia who also experience other forms of marginalization.

The recommendations outlined provide a good starting point for supporting people with dementia and their carers in their communities, in addition to the invaluable services and supportive policies that are needed to support carers in their caring role and beyond. Ideally, dementia-friendly communities should be places where all people, whether living with dementia or not, whether carers or not, should be supported in exercising their social citizenship and should be able to engage with their environments in ways that are not only free from discrimination but also actively welcoming and accessible.

## Notes

- 1 All names and identifying details have been changed to protect confidentiality.
- 2 In this article I am defining “carer” as someone who provides regular support to a friend or family member (including chosen family) with dementia. Although I use the words “caring for”, I would like to specify that care is not unidirectional. As many carers in this study indicated, they still receive many forms of support and love from the person with dementia.
- 3 For the purposes of this article, I am defining “urban” as the downtown core of Ottawa, “suburban” as the dense yet primarily residential neighbourhoods immediately surrounding the downtown core of Ottawa, and “semi-rural” as the small towns that are in the countryside but are nonetheless easily accessible and within a 1-hour travel proximity to Ottawa.

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