

## 109 年度失智友善資源整合計畫 12 月份文獻摘譯

文章	<p><b>Dementia-Friendly Neighbourhoods in Canada: A Carer Perspective.</b> 加拿大的失智友善社區：由照顧者的觀點</p>
文獻出處	<p>Silverman, M. (2020). Dementia-Friendly Neighbourhoods in Canada: A Carer Perspective. <i>Canadian Journal on Aging/La Revue canadienne du vieillissement</i>, 1-12.</p>
目標	<ul style="list-style-type: none"> <li>● 奠基於過去對失智照顧者在社區中的研究，此研究著重於照顧者在地方環境中被支持的感受或是不被支持的感受，並藉由這些經驗提出對未來的建議。</li> <li>● 此研究在加拿大渥太華及周邊地區進行，雖然無法代表全體加拿大人的觀點，但由於關於照顧者對失智友善社區觀點的文獻至今仍很有限，故期待此文章可以呈現出照顧者在社區中的經驗。</li> <li>● 從照顧者的觀點出發，並非要抹滅失智者的聲音，或是讓照顧者代為發聲；相反地，此文目的在於考量照顧者對失智友善社區的想法。雖然在大多數失智友善社區文獻中，照顧者都會被納入其中，但實則缺乏針對他們觀點來作分析的文章，因此，此篇文章選定照顧者作為主要研究對象。</li> </ul>
介紹	<p><b>失智友善社區：環境與過去文獻</b></p> <p>當今普遍為人所知的失智友善概念，大多由英國、歐洲、北美等地因應需求、設計和執行失智友善社區的經驗所得。過去文獻中大多著重於探討理論和執行失智友善社區的基本原則，僅有少數的研究提出將失智友善社區概念落實於生活中的例子，例如在英國的研究發現對失智者而言，日常生活中各種機關(如銀行、商店、大眾運輸和休閒娛樂場所)是相當重要的。</p> <p>Akhtar 等學者在研究中發現，失智咖啡館對失智者及其照顧者的日常生活中是很重要的一環；而 Brorsson 等學者則分析了，如何讓超市的環境對於失智者來說，可以更為容易取得和使用。Fleming 等學者探究了戶外空間和建築物如何影響失智者在環境中的經驗；而 Ebert 等學者則提出若社區中的民眾具有對失智症的認識，則可以改善與失智者互動的經驗和舒適度，進一步減少失智者的社交孤獨問題。</p> <p>在加拿大，他們不受”失智友善”的名詞而侷限，而將相似的概念落實於整個國家當中，例如提倡健行團體和藝術活動，讓失智者不論處在都市地區或鄉村地區，皆有更多機會參與活動。</p>
方法	<p>此研究為一項三年期研究計畫，目的在探討失智照顧者社區中的感受、經驗和社區互動的情形。本研究中的研究問題為「對失智照顧者來說，對於地點、空間和整個社區的日常經驗為何？」研究中，亦探討多位受試者的生活經驗，例如他們日常常去的地方為何？他們怎麼到達那些地點？他們都與誰溝通？他們如何得到支持？此類問題將引導我們更了解照顧者們如何使用社區的資源、並從中得到支持。</p> <ul style="list-style-type: none"> <li>● 研究設計：本研究使用描述性方法學介入(narrative methodological approach)，以期了解受試者的生活故事。三種資料收集方法為社交網絡地圖、實地訪談、和受試者為中心的攝影紀錄。這些視覺和數位資料可反映受試者在環境中的不同感官經驗。</li> </ul>

- 受試者：在社區中招募在渥太華及鄰近地區的失智者及其照顧者。共有 12 位照顧者納入此研究中，8 位女性、4 位男性，照顧者的年齡於 52-81 歲，受照顧者年齡為 59- 90 歲。所有的照顧者都與失智者同住於家中，但其中一位照顧者的妻子(失智者)在研究過程中入住一長期照顧機構。所有的訪談都在受試者家中或鄰近環境中完成，在他們真實生活環境中訪談，也更能深入了解他們的生活經驗。
- 資料收集：
  1. 社交網絡地圖：描繪出他們通常與誰溝通和互動，例如朋友、家人、鄰居、照顧服務提供者、或社區中的其他人
  2. 實地訪談：在第二次訪談中，研究者到受試者的社區中進行訪談。
  3. 受試者為中心的攝影紀錄：在第一次訪談之後，研究者交付照相機給受試者，並請他們提供 12-15 張照片，包含對他們有意義的地點、空間和物品等等，以了解在他們的生活經驗中，什麼是最重要的。而在第三次及第四次訪談中，研究者會使用受試者提供的攝影紀錄引導訪談的進行。所收集到的在攝影紀錄中，包含了健行步道、長凳、聖誕節燈飾、汽車、信箱、咖啡館、一般商店、和家用品等。

照顧者在本研究中提到很多生活的不同面向，包含社交互動、在人造和自然環境的經驗，以及他們所使用的服務和商家。以下的主題皆由他們的生活故事(關係、地點、日常活動)所集結而成。

#### 一、關係

1. 家人和朋友：照顧者表示家人和朋友通常不知道要如何幫忙，而且他們本身可能有控管情緒的困難，因此照顧者會更難以得到援手，但是，照顧者也表示有時候意想不到地得到了他人的協助，如支持團體認識的朋友，或是生活中其他服務所接觸的人們(如髮型師、店員)。
2. 鄰居和陌生人：照顧者表示對鄰居和陌生人們抱持著正面和負面的經驗。鄰居可瞻前顧後，幫忙看顧著會遊走的失智者，也幫忙倒垃圾等小事，也可以做為社交互動的來源。但部分照顧者也表示，他們經常在與陌生人或不熟識的人們互動時，感受到帶有汙名化意味的質疑。
3. 商業和服務：大多照顧者表示，他們外出選擇商家的考量，選擇大多源於社交互動和連結。照顧者與失智者一同外出時，更傾向選擇那些可以理解失智症、提供協助、並歡迎他們的店家。

#### 二、地點

1. 家：照顧者對家的描述，與周邊的鄰居和與其互動的經驗息息相關。換句話說，與鄰居人際關係的品質，深深影響了照顧者對家的感受。
2. 社區聚會地點：照顧者表示有方便可達的社區聚會場所(如咖啡館、圖書館或社區中心)，可以幫助他們建立社交網絡、降低孤獨感，也可藉由和失智者一同參與活動而維持關係。照顧者與失智者都可從社區聚會地點中獲益，他們因此而建立更多社交連結、參與社會中的活動，享受無歧視的自由感。部分照顧者也提到，社區聚會地點並非侷限於室內空間，亦可在戶外開放空間，例如設置長凳的公共廣場中，也有助於他們與他人互動。

發現

	<p>3. 最喜歡的地方：不同於社區聚會地點，照顧者通常會獨自待在最喜歡的地方，從他們日常的挑戰中紓解和放鬆。部分照顧者最喜歡的地方是自然環境(例如花園)，也有照顧者提及最喜歡的是探訪當地的建築設計，亦有照顧者最喜歡到特定的購物中心，在長凳上觀看燈飾、而讓他感到平靜。不論是室內或戶外環境，這些地方都使他們得以放鬆、重拾能量、得以喘息。</p> <p>三、日常活動</p> <p>1. 日常規律：當地環境對照顧者及失智者日常規律的影響也很大，例如對 Jack 來說，當他與太太去散步時，自然環境對他們很重要；而當他們參加每周一次的賓果活動時，當地社區中心的社交環境也扮演很重要的角色。</p> <p>2. 散步：照顧者表示散步活動在不同時間、地點將具有不同的功能，散步活動可以增進與失智者的連結、與社交環境/自然環境/自我的連結。例如，對他人微笑和揮手打招呼、看到孩子們從校車下車回家，都可以產生與他人的連結。甚至，照顧者表示很簡單的外出，看到其他人，感受到自己與這個世界的連結，都有助於維持他們的社交生活。</p> <p>3. 天氣：本研究所執行的區域，約有半年的時間處與雪季和艱困的天氣狀態，而大部分的照顧者表示雖然天氣使得外出更為困難，但他們仍舊盡可能的規律外出。對於行動不便的照顧者來說，他們以開車來取代散步，雖然天氣狀況不利於他們的外出活動，但他們仍會盡其所能地一同外出。</p>
<p>討論</p>	<p>從研究結果可得知超市和其他商店的可近性、實用性，對失智者和照顧者來說都非常重要；而社交環境對照顧者也相當重要。公共聚會的場所(如咖啡館)也都對雙方影響甚鉅，也可促使鄰居和陌生人成為照顧者的支持。此外，照顧者多次提及寵物(尤其小狗)幫助他們有更多社交連結，使他們和其他人有更多話題和社交參與。</p> <p>本研究並無深究較邊緣化人們的經驗，此可視為本研究的一項限制。人們可能因為處於邊緣族群的社區中、語言弱勢的社區、LGBTQ 族群、失能或其他障礙，而面對污名化和歧視，他們的經驗則可能會與本研究所得的結果不同。試想，若照顧者有語言的隔閡，他們將如何與鄰居互動？若照顧者為跨性別或非二元性別者，他們可能會避開那些錯認他們性別的商店嗎？不同種族的照顧者是否會因安全顧慮而避開某些街道呢？</p>
<p>建議</p>	<ul style="list-style-type: none"> <li>● 商家應為失智者及其照顧者努力，提供歡迎他們、有幫助的、容易接近的物理環境和社會環境。</li> <li>● 建議應該持續維護和廣設社區聚會地點，例如咖啡館、圖書館、一般商店和社區中心，上述地點都可能促進社交連結，其重要性應該被重視。戶外空間的設計應將如何促進社交互動納入考量，例如在公共廣場、集合地點或某些長凳設計上加入巧思。</li> <li>● 失智者及其照顧者需要部份的協助使得散步活動更為順利，例如人行道、劇平的雪地和每個社區中的據點(如公園、咖啡館、公共廣場等)。</li> <li>● 照顧者為尋求自己喜歡的空間和時間，仍需要外界支持來充電；例如，部分照顧者可以在日常活動間休息、獲得能量，而部分照顧者則需要他人代勞或是藉由喘息服務，得以休息。</li> <li>● 社區應探索更多讓失智者、照顧者與狗互動的可能性和好處，可藉由非正</li> </ul>

式的社區活動，增加雙方互動的機會。

- 由於加拿大的冬天氣候寒冷，戶外活動深受侷限，而部分加拿大年長者會出國避冬，使得失智者和照顧者所擁有的支持減少，故建議須增加討論在冬天的因應措施。
- 由於汙名化的問題很深刻地影響失智者在社區中的經驗，減少汙名化的活動是非常重要的。當想到失智友善社區的概念時，我們必須了解背後可能隱含的不同歧視和見解，故我們更需要讓這個議題曝光於大眾的面前，提升大眾的知能和做出改變。

<b>Study</b>	Dementia-Friendly Neighbourhoods in Canada: A Carer Perspective
<b>Author</b>	Silverman, M. (2020). Dementia-Friendly Neighbourhoods in Canada: A Carer Perspective. <i>Canadian Journal on Aging/La Revue canadienne du vieillissement</i> , 1-12.
<b>Objectives</b>	<ul style="list-style-type: none"> <li>■ Based on findings from a study examining the lived experiences of dementia carers in their neighborhoods, 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 neighborhoods, the combination of which has been lacking in the dementia-friendly literature to date.</li> <li>■ 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.</li> </ul>
<b>Introduction</b>	<p><b>Dementia-Friendly Communities: Context and Literature</b></p> <p>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, &amp; 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 &amp; British Standards Institution, 2015; Bartholomew &amp; 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 &amp; Eley, 2013, p. 52).</p> <p>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</p>

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.

In Canada, without necessarily being labeled "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 centers 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).

### **Carers in their Neighborhoods: 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 neighborhoods. The research question asked: What are the everyday experiences of place, space, and neighborhood 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 neighborhoods and how they are being supported locally.

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.

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. 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. 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

## **Methods**

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, neighbors, service providers, or others in their community. During the second interview, typically scheduled a few weeks after the first, I conducted a walking interview in the participant's neighborhood. For three participants with reduced mobility, I instead conducted a driving interview. 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.

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

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.

#### **Relationships**

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

##### **1. Family and friends**

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.

##### **2. Neighbors and strangers**

Carers also reported both positive and negative experiences in regard to their interactions with neighbors and strangers. Other participants echoed this sentiment, saying that neighbors 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. Neighbors were also seen as sources of latent support, meaning that the participants took comfort in knowing

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they could call upon a neighbor if needed. Some participants explained that they were confronted with stigma on a regular basis, sometimes in their interactions with strangers and acquaintances.

### 3. 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.

#### **Places**

##### 1. Home

The feelings that carers expressed about their homes were directly linked to their feelings about the neighborhood in which their home was situated, and in particular, their experience of social relationships in that neighborhood. In other words, the quality of those relationships was primarily what shaped participants’ perceptions about the emplacement of their home.

##### 2. 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 centers. 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. 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. 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.

##### 3. Favorite places

Contrary to community gathering places where they would most often go with the person with dementia, favorite 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. Sometimes carers’ favorite 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, favorite places



tended to facilitate relaxation, restoration, and even respite for many carers in the study.

### **Every day Practices**

#### 1. Daily routines

The local environment played a supporting role in shaping and facilitating those routines. 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.

#### 2. Walks

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. 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.

#### 3. 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. 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 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.

### **Discussion**

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.

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

	<p>minority communities, those identifying as LGBTQ, or those having different forms of disability, will necessarily experience their environments differently.</p> <p>For example, how do carers interact with neighbors 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?</p>
<p><b>Recommendation</b></p>	<ul style="list-style-type: none"> <li>• Businesses should strive to offer people with dementia and their carers a welcoming, helpful, usable, and accessible built and social environment.</li> <li>• Community gathering places, such as cafés, libraries, general stores, and community centers, 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.</li> <li>• 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 neighborhood, for example community mailboxes, cafés, parks, or public squares.</li> <li>• Carers should be supported in seeking out their favorite 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 favorite place means relying on the assistance of others or on respite services, which should be made more plentiful and accessible.</li> <li>• 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.</li> <li>• 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.</li> <li>• The vital work of reducing the stigma related to dementia must continue, as this has a direct impact on people’s experiences in their neighborhoods and communities. When imagining what dementia-friendly neighborhoods 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.</li> </ul>