Wellbeing, Space and Society 9 (2025) 100314

Contents lists available at ScienceDirect

Wellbeing, Space and Society

journal homepage: www.sciencedirect.com/journal/wellbeing-space-and-society

Exploring the awareness of changes in outdoor mobility and the influence of the neighbourhood environment among people living with dementia in British Columbia, Canada

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ARTICLE INFO

Keywords:
Aging
Dementia
Dementia-friendly and inclusive communities
Age-friendly communities
Urban design and planning

ABSTRACT

Fostering an inclusive neighbourhood environment is a critical part of the social responsibility to support people living with dementia to participate in community activities and maintain autonomy, identity, health, and wellbeing. Dementia scholars and advocates have emphasized the need to understand how people living with dementia interact with and adapt to the neighbourhood environment. This understanding will inform dementia-inclusive policy and practice to create enabling physical and social environments. The present study explores the experiential knowledge of people living with dementia gained through their awareness of age and disease-related changes, perceptions of the neighbourhood environment, and adaptive processes to maintain outdoor walking. Sequential semi-structured sit-down and video-documented go-along interviews were conducted with 14 people living with mild to moderate dementia in Metro Vancouver, British Columbia. Thematic analysis produced two themes: 1) Awareness of needing to adapt to changing abilities to walk in the neighbourhood, and 2) Heightened awareness of risk factors and influence of neighbourhood environment on outdoor mobility adaptations. Recognizing people's awareness and adaptive responses, and cultivating relational understandings of the agency and capacities of people living with dementia are integral to creating inclusive neighbourhood environments that enhance the capabilities for participation in the community.

Introduction

Promoting healthy aging has become a key priority in research, policy, and practice, and has wide-ranging implications for older adults' access to appropriate healthcare and supports, and their capacities for activity and participation (World Health Organization [WHO], 2017, 2021). An integral part of promoting healthy aging is the focus on brain health, cognitive functioning, and risk reduction for dementia (WHO, 2012). Dementia is an umbrella term for symptoms, such as difficulties with memory, language, communication, decision-making, and way-finding, caused by several neurodegenerative diseases (WHO, 2012). These challenges of living with dementia are compounded by social, environmental, and institutional barriers due to 1) gaps in diagnosis, care and support, 2) stigma and a lack of public awareness, and 3) denial of involvement of people living with dementia in decision-making (Milligan and Thomas, 2016; WHO, 2017). In Canada, the population living with dementia is estimated at 771,939, and this number is expected to increase to 1 million by 2030 (Alzheimer Society of B.C. 2024).

Dementia-friendly and inclusive communities (DFC) initiatives within and outside Canada are seeing the involvement of local governments, service agencies, and businesses in facilitating social inclusion and accessibility of community spaces and services for people living with dementia and their family members (Alzheimer Disease International [ADI], n.d.; Public Health Agency of Canada [PHAC], 2019; World Health Organization [WHO], 2017). The DFC framework highlights the role of the built environment, urban design and planning (UDP), and accessibility as integral parts of dementia-inclusivity (Hebert and Scales, 2019; WHO, 2021). However, DFC initiatives in UDP have been found to be disconnected from the lived experiences and the realities of accessibility on the ground for people living with dementia, which is

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https://doi.org/10.1016/j.wss.2025.100314

Available online 13 October 2025
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representative of a wider knowledge gap about the lives of people with dementia in non-institutionalized settings (Seetharaman et al., 2025; Ward et al., 2021a). Further, the DFC framework has been criticized for offering generic advice that overlooks the particularities, histories, and unique socio-spatial relations of people living with dementia in different places (Ward et al., 2021a).

Neighbourhood built environment through the lens of lived experience of dementia

Understanding how people living with dementia experience their environment and adapt to the demands of conducting activities in the community is a necessary precursor for DFC initiatives in UDP (Kuliga et al., 2021; Rohra et al., 2021). Neighbourhoods are defined by spatially based attributes (e.g., demographics, infrastructure, services and amenities, social networks, local identity) that are associated with clusters of residences or other land uses (Galster, 2001, p.2112). The extent to which neighbourhoods support older residents' needs depends on the physical, social (i.e., the community in which people are embedded), and functional components (i.e., local services, programs, and infrastructure) (Padeiro et al., 2022, p.352). A supportive neighbourhood built environment is particularly relevant for people living with dementia, given the cognitive challenges that they experience in 1) dividing attention between multiple concurrent environmental stimuli, 2) making quick informed mobility and navigation decisions, and 3) maintaining their sense of orientation in the outdoors (Brittain et al., 2010; Brorsson et al., 2016; Ward et al., 2018).

The early years of the dementia journey are known to be marked by active processes of learning to live with and finding ways to cope with the difficulties of daily life (Dooley et al., 2021). In this period, some people living with dementia have been found to respond to changes in their abilities and cope with dementia-related challenges by implementing goal-oriented strategies to meet their needs (Niedoba and Oswald, 2024). Strategies practised in the neighbourhood environment include avoiding places that feel overstimulating (e.g., with high levels of traffic, noise), unsafe (e.g., dimly lit, associated with crime), or unfamiliar, and using environmental cues and support from care partners, neighbours, and assistive technology (Biglieri and Dean, 2021; Olsson et al., 2019; Sturge et al., 2021). These adaptive strategies reflect people's expressions of agency (e.g., maintaining or changing activity spaces, using aids to overcome functional limitations) and belonging (e.g., participating or withdrawing from activities and places based on familiarity) (Niedoba and Oswald, 2024). Examining adaptive processes is related to the study of subjective aging, i.e., how individuals reflect on their development and understand their experiences of growing older (Diehl et al., 2012). A recent development in subjective aging is the concept of awareness of age and disease-related change (AADRC), which encompasses states of awareness triggered by internal and external factors that represent the realization of changes in behaviour and ways of experiencing life as one grows older (Diehl and Wahl, 2010). Previous research has emphasized the importance of accounting for AADRC and resulting self-knowledge in the study of adaptation (Diehl et al., 2014; Dutt et al., 2018).

The concept of awareness among people living with dementia has been defined as "a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications" (Clare et al., 2012, p. 140). While transitioning into living with dementia, people go through cycles of registering, reacting to, and explaining dementia-related changes, experiencing impacts of these changes, and adjusting to the changes as part of their growing awareness (Clare, 2003). Their awareness is conceptualized as a product of 1) cognitive changes in memory, executive function, and ability to comprehend new information about their condition and apply this knowledge in everyday life, 2) personality, coping style, values and beliefs, and life experiences, and 3) interpersonal interactions with care partner, family, friends, and service providers (Clare, 2004, p.169).

This study proposes that the built environment (i.e., the physical contexts of older adults' out-of-home activity that includes street-level features, such as sidewalks and street crossings, and community-level features, such as land-use, density, and open/public spaces (Padeiro et al., 2022, p.352) is also an important factor informing AADRC. Informed by the social model of disability, our view of the built environment is in terms of the capabilities or opportunities it provides for people to meet their primary needs and have the freedom to live their lives based on their goals and values (Shakespeare and Watson, 2018; Pineda, 2020). In the context of out-of-home activity, the neighbourhood built environment is seen as facilitating freedoms and opportunities for people to be mobile, to reach activities of their choosing, and participate in these activities.

Research objectives

The concept of AADRC allows us to explore people's insights into and awareness of disease-related changes in their lives and harness their subjective 'experiential knowledge' (i.e., lived experiences converted consciously or unconsciously into personal insights that enable the person to cope with illness and disability) (Halloy et al., 2023, p.409). The present study focuses specifically on AADRC in the context of outdoor walking in the neighbourhood. Our research questions are: 1) How do people living with mild to moderate dementia become aware of the need to adapt to walking outside in their neighbourhood? and 2) How does this awareness influence their attitudes, perceptions, and behaviour related to walking outside in the neighbourhood? The study is part of the first author's doctoral dissertation, which aims to generate knowledge based on the lived experiences of people living with dementia and guide municipal planners in understanding diverse outdoor environment accessibility needs and the role of the neighbourhood built environment in fostering dementia-inclusivity. The dissertation is part of a larger community-based mixed-methods research project titled Dementia-inclusive Spaces for Community Access, Participation, and Engagement (DemSCAPE) that was conducted in two cities in British Columbia, Canada: Vancouver and Prince George, to explore dementia-inclusive planning and design through engagement with people with lived experience, care partners, and representatives from local government and dementia support and advocacy organizations.

Methods

Research paradigm

This study is situated within an interpretivist paradigm (Willis, 2007). In this study, knowledge of the lived experience of people living with dementia hinges on direct interaction with them and understanding how they make sense of dementia-related changes in their lives (Beard, 2004). Research conducted over the last three decades increasingly emphasizes 'involvement' and research 'with' or 'by' people living with dementia instead of research 'for' or 'about' them using proxy respondents (Bethell et al., 2018; Murphy et al., 2015; Pickett and Murray, 2018).

Participants and context

Participants were selected based on 1) self-declared diagnosis of mild to moderate dementia or mild neurocognitive disorder (MND), 2) residence at home in the community in Metro Vancouver (M.V.), and 3) practice of walking outside (i.e., regularly or occasionally). Participants were recruited as part of the DemSCAPE project with the help of local government bodies, advocacy and community-based service organizations, and clinicians. Recruitment strategies included 1) distributing flyers to local advisory groups, support groups, seniors' centres, and dementia support organizations, and 2) phoning patients screened by clinicians at the Centre for Brain Health at the University of British

Columbia. The sample (see Table 1 for sample characteristics) consists of 14 participants ranging in age from 61 to 87 years (mean age: 75.7 years). Seven participants were men and seven were women. Ten participants were part of spousal care dyads, of which eight care partners supported the participants in study activities and contributed insights on their outdoor mobility experiences. Four participants lived alone. Participants were residents of six municipalities in M.V., ranging in population from 21,360 to 692,310 (Metro Vancouver, 2024a), and nine participants resided in 'urban centres' (i.e., "priority locations for higher density housing, employment and services, commercial, cultural, entertainment and institutional uses" (Metro Vancouver, 2024b, p.1)).

Data collection

Data collection was conducted from June 2022 to November 2022. The following sequential interviews (60–90 min) were conducted approximately a week apart with each participant. The procedures and tools used for these interviews have been described in detail in a previous paper (Seetharaman et al., 2023).

1) *Sit-down interview 1* was a structured interview focusing on weekly routines of outdoor activity and conducted using a questionnaire to identify where, when and how often the participant walked in their neighbourhood.
2) *Sit-down interview 2* was a semi-structured interview to explore the participant's motivations and preferences for walking outside and their awareness of changes in their walks and in their neighbourhood environment.
3) *Go-along interview* (Carpiano, 2009) sought to explore in-situ how participants interacted with their neighbourhood environment while walking outside. The participant and their care partner (in the case of dyads) walked with the first author on a route of the participant's choosing in their neighbourhood and talked about their experience of walking outside, the problems they encountered and how they coped with them, and how they remembered and identified places and routes. The average distance covered in participants' go-along interviews was 0.9 miles, ranging from 0.5 to 1.7 miles. The interview sites included places of nature (e.g., parks, beach, lake) ($N = 7$), neighbourhood streets ($N = 4$), and places of education and business (e.g., university, secondary school, café) ($N = 3$). While the first author conducted the interview, a research assistant walked a few metres behind the participant to video-record the interview using a GoPro camera (i.e., head-mounted or handheld and connected to wireless mics worn by the participant and the first author). Twelve out of fourteen participants also participated in secondary video-recording using another GoPro camera (i.e., worn on a hat or a chest harness) to record their point of view and what they were noticing and observing in their environment during the interview.
4) *Sit-down interview 3* was a semi-structured interview that expanded on key issues discussed during the go-along interview that were specific to each participant. The interview employed the video-elicitation method (Li and Ho, 2019). Participants were shown select clips extracted from their go-along interview video data that encapsulated key issues and asked follow-up questions.

Data analysis

Participants' responses to the questionnaire administered in sit-down interview 1 were analyzed through descriptive statistics to identify frequencies for their outdoor mobility characteristics. Data generated from sit-down interview 2, go-along interview, and sit-down interview 3 were thematically analyzed (Braun et al., 2019). The interview transcript data were analyzed using NVivo qualitative analysis software. Transcripts were read line by line to generate initial codes. Codes were reviewed to ensure that they were meaningful and distinct from each other. Broader themes were identified into which the codes were grouped and sorted. Themes were revised and refined by collapsing similar themes and breaking down overly broad themes. After re-reading coded data extracts, descriptions of codes were written to capture the essence of the data. The (go-along interview) video data was analyzed using Transana qualitative analysis software. The videos were synchronized with the corresponding interview transcripts, and together these video-transcripts were re-coded using the coding framework generated in the textual analysis of interview transcripts. Through this process of recoding, additional codes were generated to capture non-verbal and visual aspects of participants' walking behaviour

Table 1
Participant Demographics.

Participant	Age (at the time of interviews)	Gender (M: Male, F: Female)	Ethnicity	Dementia Diagnosis and Year of Diagnosis	Other Health Conditions	Care Partner (if applicable)	Duration of Residence in City (at the time of interviews)
P01	73	F	European	Mild neurocognitive disorder (MND) (2011)	Chronic Obstructive Pulmonary Disease (COPD)	CP01; spouse	10 years
P02	87	M	European	Parkinson's Disease Dementia (2021)	-	CP02; spouse	32 years
P03	73	M	European	Lewy Body Dementia (*year unknown*)	Postural Hypotension	CP03; spouse	1 year
P04	71	F	European	Alzheimer's Disease (2012)	-	CP04; spouse	47 years
P05	80	M	European	*Unknown* (2018)	Osteoarthritis	N/A	15 years
P06	87	M	Chinese	Vascular Dementia (2017)	High Blood Pressure and Cholesterol	CP06; spouse	1 year
P07	80	F	Chinese	MND (*year unknown*)	Stroke	CP07; spouse	20 years
P08	76	F	European	Alzheimer's Disease (*year unknown*)	-	CP08; spouse	21 years
P09	61	M	European	MND (2021)	Chronic Fatigue, Depression, HIV	N/A	6 years
P10	77	F	European	*Unknown* (2017)	-	N/A	10 years
P11	82	F	European	*Unknown* (2017)	Osteoarthritis, High Blood Pressure, Gastroesophageal Reflux Disease (GERD)	CP11; spouse	6 years
P12	78	M	European	Parkinson's Disease Dementia (2017)	-	CP12; spouse	10 years
P13	65	F	European	MND (2017)	Neuropathy, Auto-Immune Disorder, COPD	N/A	10 years
P14	70	M	European	Lewy Body Dementia (2010)	Stroke, Seizures	CP14; spouse	11 years

observed in the video data. These codes reflected how participants 1) observed various aspects of the outdoor environment and searched for and comprehended spatial information, 2) were watchful of various risk factors on the walking route, 3) maintained gait and balance and manoeuvred mobility devices around uneven surfaces, 4) expressed feelings of pain, fatigue, shock, and surprise, 5) interacted with other people on the street, and 6) received assistance from their care partners.

Research ethics

The study received ethics approval (H21-03552) through Research Ethics BC Network from the institutional research ethics boards at Simon Fraser University and the University of British Columbia. A process consent approach allowed for informed consent to be obtained from participants and care partners at each stage of the research process (Rivett, 2017; West et al., 2017). Participants had opportunities to ask questions about the study and be reminded about critical study details, and make informed decisions to participate at each stage (Hellström et al., 2007). Participants' informed consent was ascertained based on their understanding of the different research activities (Dewing, 2007; Heggestad et al., 2013), which was well demonstrated by all participants at each stage of the study.

Findings

Participants' experiences of outdoor mobility adaptations are represented through two themes: 1) Awareness of needing to adapt to changing abilities to walk in the neighbourhood, and 2) Heightened awareness of risk factors and influence of neighbourhood environment on outdoor mobility adaptations.

Table 2 outlines key characteristics of participants' outdoor mobility routines. Nine participants indicated walking as their primary mode of mobility, three reported being driven by their care partner, and two reported using public transit and driving, respectively. Ten participants reported walking outside at least once a week, and three of these participants walked outside in their neighbourhood every day.

Awareness of needing to adapt to changing abilities to walk in the neighbourhood

The first theme presents participants' insights on their motivations to remain mobile in their community, becoming aware of changes in their outdoor walking abilities, and needing to adapt their outdoor walks.

Motivation to maintain outdoor mobility

Participants' adaptations to changing walking abilities were motivated by their views on physical activity and health. They meant to continue outdoor walking, so as to preserve extant physical capacities. One participant said, "It's important to move–to move myself, even if I'm [finding it] difficult […] But I persist to walk, [because] I have to move…for health" (P14). Another participant's motivation to walk outside reflected the prioritization of maintaining extant abilities over regaining physical abilities from the past: "I walk because I know I must walk. But I don't do it as a challenge […] I just do it to stay mobile" (P05). Prioritizing continued walking was also motivated by the fear of further loss of walking abilities. One participant said, "If you don't keep moving, […] the next step is the wheelchair. That's what happens, eh, [because] I've got shin splints and stuff' (P11). The fear of losing extant physical capacities motivated another participant to prioritize exercise-focused walks that challenged him and helped him build strength, rather than leisure walks: "I'm a little bit afraid that if I go for a leisure or leisurely walk down to the seawall that I won't have a lot of energy… that's going to be my whole […] that'll be it" (P09).

For a participant who lived alone, walking was simply a means to travel the distance between public transit stops and her home or activity destinations. Her motivation to engage in leisure walking had decreased following the loss of social connections in her neighbourhood that were crucial to her outdoor walking routine in the past: "I don't really have anyone that I go out with at all. My neighbour who used to live right across the hall from me—we used to do lots together […] Now she lives over in [Vancouver Island]" (P10). Beyond nurturing interpersonal relationships, maintaining outdoor mobility for another participant who lived alone meant cultivating a sense of belonging by participating in different out-of-home activities and staying engaged in the community:

> I like being involved in my community. Because it just makes me feel secure. […] I'm just not here as a visitor. I'm participating. […] That's why I do silly stuff like go to McDonald's every day for the same cup of coffee. (P13)

Awareness of decreased energy and stamina

The motivation to sustain outdoor mobility and maintain health and well-being was balanced alongside priorities of being proactive, cautious and careful while walking outside. Participants reported taking stock of these changes in mobility (e.g., balance, speed, stamina) following the onset of dementia, other health conditions, and age-related changes and modifying their walking behaviour to align with their priorities. For example, participants reported being aware of their

Table 2
Characteristics of Participants' Outdoor Mobility.

Participant	Modes of Mobility Practised (Most to least preferred)	Extent of Participants' Mobility	Frequency of Outdoor Walking	Purpose of Outdoor Walks (Most to least important)	Mobility Assistive Devices Used
P01	Walking; Getting Driven by CP	Within and beyond neighbourhood	>1x /wk	Leisure; Functional	
P02	Getting Driven by CP; Walking	Within and beyond neighbourhood	<1x /wk	Physical Activity; Leisure	Walking sticks
P03	Driving; Walking	Within and beyond neighbourhood	<1x /wk	Leisure	
P04	Getting Driven by CP; Walking	Within Neighbourhood	≥1x /wk	Leisure	
P05	Walking	Within Neighbourhood	<1x /wk	Physical Activity	Cane
P06	Walking; Getting Driven by CP	Within Neighbourhood	>1x /wk (every day)	Cognitive Stimulation; Leisure	Walker
P07	Walking	Within Neighbourhood	>1x /wk (every day)	Physical Activity; Functional	
P08	Walking	Within Neighbourhood	>1x /wk	Leisure; Functional	
P09	Walking; Transit; Driving	Within and beyond neighbourhood	>1x /wk	Functional; Leisure	
P10	Transit; Walking	Beyond Neighbourhood	<1x /wk	Functional	
P11	Walking; Getting Driven by others	Within Neighbourhood	>1x /wk	Physical Activity; Leisure	Walker
P12	Getting Driven by CP; Walking	Within and beyond neighbourhood	>1x /wk	Physical Activity; Leisure	Walker
P13	Walking; Transit	Within Neighbourhood	>1x /wk (every day)	Functional; Physical Activity	
P14	Walking; Transit	Within Neighbourhood	>1x /wk	Functional; Physical Activity	Cane

decreased walking speed and planned their walks accordingly. One participant said: "I've slowed down incredibly. […] I'll take my time now, because I'm very cautious […] I don't walk fast anymore. […] [I'm] just conscious of my own self. I'm just a lot more careful" (P10). Another participant with partial paralysis caused by a stroke mentioned becoming wary of walking fast and anxious about losing his footing and framed walking slowly as a proactive measure: "I don't want to miss my step. That's the only thing I'm worried about. […] Once I go a bit faster—because […] the left side is my stroke. […] my foot doesn't move the way I want to" (P14). Maintaining a safe unhurried walking pace required taking additional proactive measures, e.g., monitoring the pedestrian signal to determine a safe crossing gap to cross the street at a comfortable speed: "The street sign is green, but […] it doesn't count down. So, I'll go across. But once it starts to count down, I'll usually wait because it countdowns really fast. […] It's only since…I've been aware of this condition" (P10). However, some participants (e.g., walker users) felt the need to walk at a faster pace, citing insufficient crossing time provided by the pedestrian signal. At non-signalized intersections, one participant felt obliged to drivers who gave her the right-of-way to not take up much time crossing the street and hence tried walking faster:

> I feel I'm too slow at the crosswalk. [Because] the cars there stop, eh? So, I try to go across as fast as I can. And I give them a wave just to say thank you for waiting. People have a life besides waiting for an old lady to cross the road, eh? (P11)

Participants paced themselves by taking frequent breaks to recuperate from discomfort and fatigue during outdoor walks. Noting reduced stamina and comfort while walking with arthritic pain, one participant described relying on her walker to sit and rest at regular intervals: "I use the walker. It's got a chair. So, when I get tired, I can sit down. […] I do have to sit down more often. That's a change. […] Otherwise, I couldn't walk outside." (P11). Care partners helped enhance participants' awareness of their need to stop and rest while walking. One participant said: "When I go walking with [CP02], often toward the end of the walk she notices that I'm walking more unevenly. And she might suggest to have a break. And we do" (P02).

Participants also responded to their awareness of decreased energy and stamina by modifying their walking distance. One participant discussed how she found an appropriate distance for her leisure walks on a long unidirectional route along the waterfront in her neighbourhood, "You have to remember you have to go back [home] (laughs). I remember when I first came here (the seawall), I went a little too far. I was very tired" (P08). This participant had grown to identify landmarks along this route that served as destinations for her walks, helped her track the distance covered, and reminded her when to turn around and return home. She said, "In my mind—because we do this so often—I just know if I'm in the…if I feel like just going to [destination] or if I'm going to do a longer walk" (P08). Another participant coped with chronic fatigue also using pre-determined 'milestones' on the waterfront route by assessing his stamina and deciding when and where to cut his walk short: "I can say, 'Okay, can I make it for the next milestone,' which would be something that I would think in my head, 'If I can make it to this far, then I'll reassess'" (P09).

Another strategy to modify walking distances to combat fatigue was walking closer to home. A dyad prioritized destinations close to home as it allowed for better problem-solving if the participant experienced unforeseen challenges while walking outside: "If we went up to the library, and he all of a sudden started getting tired, […] there's places to sit, and I could get him back home safely. I could come back and get the wheelchair if I had to" (CP12). In one dyad's case, walking shorter distances close to home was necessitated by the care partner's injury. The participant drove his car on most of their joint outdoor trips, and their outdoor walking routes were limited to paths within their housing complex. The participant explained, "[CP03] can't walk as far. So, even if it's just down the road, maybe 200–300 yards— […] usually— there's the pub, just up the road there. […] it's within easy walking distance. But we drive" (P03). His care partner expressed concern about the impact of these adaptations on the participant's capabilities (i.e., to walk more frequently to nearby neighbourhood destinations): "I look forward to when I'm fully healed, and can walk more […] I feel like I'm kind of pulling [P03] down— to my level where—he could actually probably walk a lot further than I could" (CP03).

While most participants predicated their experiential knowledge and AADRC on previous outdoor walking experiences, they also reflected on their walking characteristics (e.g., gait, posture) when they viewed clips from their go-along video recording in sit-down interview 3. Participants were self-aware and critical of the changes in their mobility that they had not been aware of. The videos prompted reflections on age norms, stereotypes, and anxieties about AADRC:

> I don't like how I walk. […] I looked like I'm—like it's hard. Like it's…heavy.[…] It's just my gait…is weird. I've never seen myself […] I'm thinking, 'wow, is that a normal gait? Do I have a good gait for a 61-year-old or a bad gait for a 61-year-old? (P09)

> Doesn't look good, does it?… I wouldn't believe it if I didn't see it. […] I didn't think I'd ever get that old. (P11)

> I look like 80 or 90. And I'm only 70. […] I look older. It's not good. I should be walking. But it's not working. (P14)

Awareness of susceptibility to disorientation and need for familiarity

Participants spoke about becoming aware of their susceptibility to getting lost in the outdoors. Recalling his experiences of becoming lost early in his dementia journey, one participant spoke about learning to define parameters for his outdoor walks: "In 2010, a lot of time, the police will drive me home. Because I was lost. […] I would walk around the corner and I would head up to [mountain in neighbouring city]. […] I learned my limit" (P14). This participant's awareness of needing a clear purpose, activity, and destination to direct his focus and concentration and stay oriented while outside was explained by his care partner: "[P14] likes to focus on something that he's going to be doing—if he's going somewhere and he has a goal […] It's almost like he needs that. He says, 'Okay, I know where I'm going now'" (CP14). Highlighting the precarity of staying oriented while outside, the participant emphasized the value of writing to-do lists at home as a preparatory measure to remind himself of the purpose of going outside and avoiding straying from plans:

> When [CP14] comes with me and I go to [grocery store], I don't spend too much time because I know exactly what I need. […] I do a list every week. […] I learned that from [neurologist] to be able to […] focus […] I go [to the store]. I got to get to [the items on the list]. That's it! If I go—if she forgot something, I don't even know where I am anymore. It's amazing how fast you can lose it. (P14)

For the above participant, part of learning his 'limit' and avoiding becoming lost was moving within places and routes that were familiar: "[CP14] will invite me somewhere that I'm not used to. I really don't want to go. […] I lose it. […] it's not good for me […] I remember some areas where I am. […] If I don't, I'll get lost" (P14). Participants identified precise spatial locations in their neighbourhood as zones of familiarity. One participant spoke about a familiar route around a neighbourhood park where she could walk confidently and safely: "I love walking around [the park]. […] I [am] used to our park. […] Otherwise, I fall down. I'm so scared. I don't recognize what is going on. When you have dementia, you forget very fast" (P07). Another participant delineated her walking radius within a two-block segment of the street she lived on: "Sometimes I walk by myself, but I don't go off the block. […] It's so familiar to me. I can just go. […] I really don't know… this area very well. I wouldn't like to get lost" (P11). This participant had recently (i.e., six years ago) moved to the city where she lived. For a couple of participants who had lived in their neighbourhoods for three to five decades and were well aware of routes in their neighbourhood,

becoming lost was not cited as a concern. Reflecting on his familiarity and spatial knowledge of the neighbourhood environment, one such participant said, "Because I have walked [routes in the neighbourhood] for years. […] The last year or let's say last two years, my condition has been brought to the fore. Before that, I did a lot of walking" (P02).

Prioritizing familiarity while walking outside was also integral to exercising autonomy. For one participant, choosing a compact and familiar walking radius enabled her to walk independently in her neighbourhood. However, reflecting on facilitating the participant's autonomy later in their dementia journey, the care partner said, "I walk with [P11]. At times, she'll come home by herself. […] I find that I feel safe to let her do that. *Right now*. There may be a time when I'll have to say, 'can't do that anymore" (CP11). Given that familiarity was integral to participants' wayfinding and problem-solving abilities to walk outside, changes in the stability of the neighbourhood environment posed challenges. New development and construction in neighbourhoods signalled the closure of places that used to be important landmarks for participants. One participant said, "I have to really concentrate where I am. [Because] if [places] change too much […] then you're asking yourself […] 'Where am I?' It doesn't take long for me to get lost" (P14). Another participant spoke about her efforts to familiarize herself with changes in the environment, highlighting her awareness of needing more time to get used to and 'memorize' these changes:

> [Houses] change a lot around this area. […] You take two-three months to [get] used to […] when you [are] walking—for [people living with dementia], that's a new house and maybe…maybe 'wrong street'. [When] your mind is…young, that time, it's okay, they change. Getting old, I don't—I don't think so. We're not used to anymore. (P07)

While most participants limited their outdoor mobility to familiar spaces in the neighbourhood, for some participants, non-routine activities required going to places (i.e., beyond their neighbourhood, in a different city in M.V.) that were less familiar to them (and less frequently visited). One participant spoke about needing to be proactive and prepare himself at home by repeatedly reviewing the trip itinerary and route directions to ease the anxiety of not knowing the location of his destination well enough:

> If it's not a place that I know, I'm just very dependent on Google Maps. […] I just have to plan more […] Maybe that's the thing with neurocognitive disorder—is that, I might look a day or two before the appointment to plan […] the hour before or whatever it is, I'm still looking, not wanting to get confused or lost. And then as I'm going, I'm checking. So, there's a bit of insecurity […] I know how to get to [street] walking from here. But I second-guess it. (P09)

Some participants expressed an interest in going on leisure walks to places in their neighbourhood that were away from their regular walking routes. These insights came from participants who made route decisions and walked along with their care partners. In some cases, the care partners took the lead in planning walking routes that they considered safe. Reflecting on walking on a different route in his neighbourhood, one participant said, "Depends on [CP06] being agreeable with me or not. […] Next time, I will possibly walk the other way" (P06).

Heightened awareness of risk factors and influence of neighbourhood environment on outdoor mobility adaptations

The second theme presents participants' increased awareness of the influence of the neighbourhood environment on their outdoor mobility through experiences of encountering different risk factors. Participants noted a shift in how they perceived the outdoor environment while walking outside—from not giving it much thought in the past to becoming more vigilant of their surroundings. One participant said, "I'm really more alert to things around me now—much more alert than—before I just used to go and not be bothered about anything" (P10). Participants' increased awareness of risk was linked to environmental factors, such as insufficient or blocked sidewalk space, trip/fall hazards, obstacles at street crossings, sloped surfaces, absence or unclear delineation of bike lanes, noise, and street violence and substance use.

Participants' heightened awareness of risk was associated with a perceived lack of support from the neighbourhood environment to feel secure and at ease while walking outside, as a result of which, they felt the onus was on them to protect themselves. Participants experienced a range of challenges in detecting, paying attention and appropriately responding to neighbourhood environmental factors that posed risk to them. For example, participants spoke about becoming aware of changes in their vision and perceiving risk in aspects or features of the outdoor environment that they had previously taken for granted. Low peripheral vision caused by a stroke challenged a participant's ability to detect the presence of road users in his vicinity when they were in his blind spot. He said, "I need to be careful to look around to make sure there's no bikes around…because I don't see on the right or the left" (P14). A heightened awareness of risk associated with vehicular traffic prompted a shift in the routes participants preferred for outdoor walks, particularly leisure walks. These routes were on dedicated walking paths (e.g., in a neighbourhood park, along the waterfront, or at a university campus) cut off from vehicular traffic and, in some cases, also bikes and scooters. One participant said, "That's why I like to go to the seawall […] certainly along the seawall for the most part, I don't have to deal with cars" (P09).

Participants discussed the need for increased awareness of outdoor environment accessibility since the onset of dementia. A care partner said, "You have to really concentrate, I think. Since [P12] has had his Parkinson's, in this situation we really pay attention to what's accessible and what's not, and there's not a lot of accessibility" (CP12). This participant found it challenging to detect and differentiate unmarked (i.e., without visual contrast) damaged sections on the sidewalk that hampered his mobility (e.g., when the wheels of his walker got caught in heaved and cracked sidewalks) (see Fig. 1). His care partner said, "The [tree] roots pulled up the brick. […] Sometimes the walker will get stuck. It doesn't have the really big wheels so that it can negotiate things like that" (CP12).

Participants also reflected on how their heightened awareness of risk was associated with walking outside at certain times. Ambient light levels were associated with the difficulty of detecting trip hazards on the sidewalk while walking at night. One participant said, "I wouldn't want to come out at night by myself. […] the sidewalks are uneven. And that's a way that you can trip in the dark" (P13). Having a clear view of pedestrian movement on the sidewalk was important to support another participant's adaptive behaviour to mitigate his anxiety while walking on crowded sidewalks of a main street during peak hours. He said, "When I walk, I get a bit agitated. Then I'll stop and do a little bit of breathing. […] If there's too many people that I see, then I will stop and let them go" (P14). Obstacles on sidewalks interrupting sightlines made it challenging for this participant to detect the presence of people, places, and other objects in his path of travel while walking in crowded areas. The participant noticed that the transit shelters with advertisements on the sidewalk (see Fig. 2) compromised his ability to see what was ahead on the sidewalk: "You cannot see what's coming. Sometimes, you could have a bike or wheelchair […] And you can't see it. […] People don't realize it" (P14).

Untrimmed bushes obscuring visibility of neighbourhood trails (see Fig. 3) were found to trigger perceptions of risk of the unknown for another participant. The participant's awareness of the triggering nature of these places prompted her to walk to the other side of the road before approaching the trails to allay her anxiety:

> Part of my dementia is an increased anxiety. And it can be extremely uncomfortable if you don't sort of find a way to deal with it before it gets very strong. […] That pathway down, I suspect it's a homeless camp down there. […] I *think* I don't have a problem, but obviously I



Fig. 1. *"(Walker gets stuck on damaged sidewalk around tree and requires researcher's support to manoeuvre) You see? It's pretty difficult"* (P12).



Fig. 2. *"They're putting the signs there. […] The advertisement sign they've put there, which is wrong"* (P14).

do. So, I just cross the street, go a little bit past and then go back where I feel comfortable […] If the bushes were all cut, it would feel better, because then one could see. (P01)

Other women participants also spoke about their heightened awareness of risk in relation to perceptions of other people on the street or in crowded public spaces. They described their efforts to avoid being perceived by other people as weak, vulnerable, or defenseless:

> I'm just leery of how…people react to me being a little antsy […] I can't believe that's me. But that's just it. For someone that's travelled this whole world and basically on her own, and then I find myself in this situation. It's–it's unnerving to me. (P10)



Fig. 3. *"I would probably still cut across just to try and ease some of that anxiety, so it doesn't grow to an insurmountable kind of thing"* (P01).

> I don't go out on my own at night anymore. […] I don't want to look weak. I don't want to look like I'm a target. […] sometimes I'd just carry my card on me. In my back pocket. […] I'm an older woman, by herself, so I just downsize what I–what it looks like. […] otherwise…I'm just—you're–you're putting yourself out there to be–be vulnerable. […] I know a couple of friends, acquaintances who've gotten their purses grabbed, and they've been pushed off balance because they look vulnerable. (P13)

Channelling heightened awareness of risk and adapting proved challenging when there was a surplus of hazards in the neighbourhood environment, demanding participants to simultaneously process diverse and disparate stimuli. Describing the cognitive impact of paying attention to a surplus of risk factors, one participant said, "It makes it unclear what I need to do first" (P13). For this participant, negotiating damaged sidewalks in her neighbourhood demanded all her attention to avoid trip hazards. However, doing so prevented her from being able to take stock of other aspects of the environment while walking: "I'm always looking down. […] The walk can be difficult, because then I can't see what's going on around me. So, I just try and…try and keep my eyes going everywhere" (P13). Her efforts to avoid trip hazards posed by sidewalk damage in her neighbourhood (see Fig. 4) also had the undesired effect of compromising her ability to maintain balance and avoid falling: "When I focus too much on where I'm walking…whether it's a bump in the sidewalk or a root […] It does start to affect my balance. […] because I just got too many things to think about" (P13).



Fig. 4. *"I've been walking this route for ten years, but still, if […] I've got stuff on my mind, or I'm not thinking, (gestures at joint displacement on sidewalk with her foot) it's very easy to trip on"* (P13).

Participants indicated the usefulness of environmental supports that helped alleviate the cognitive demand associated with heightened awareness of risk in the outdoor environment by providing direct and clear cues to safely negotiate potential risk factors. The need for such support was particularly apparent at street crossings. Participants expected the pedestrian signal to clearly indicate when to and when not to cross and which way to cross the street, taking the onus off them to determine a safe crossing gap. For this reason, most participants felt more secure crossing signalized street intersections than those that were non-signalized. One participant said, "I'm comfortable where there's […] a controlled crossing. […] it's when you don't have them that the problems occur […] when drivers wanting to turn right […] being hesitant to when they can or when they cannot turn" (P12). Even signalized crossings had their share of issues that exacerbated the cognitive demand associated with crossing the street. One participant spoke about the confusion caused by auditory cues provided by the pedestrian signal at a street crossing in her neighbourhood: "The 'beep beep, beep'—sometimes even now I wonder, 'What's beeping? Which one is beeping? Is it for me or is it for the other way going across.' I have to really—you have to really look" (P13).

Care partners played a significant role in augmenting participants' awareness and attention to environmental risk factors while walking outside. Their support was deemed necessary by participants to overcome the lack of supportiveness of the outdoor environment. Describing his care partner's active involvement in monitoring risk factors, one participant said, "When [CP06] finds the area is not that secure, she either stands beside me, or else prevents me from going" (P06). His care partner added that this support was critical due to lapses in the participant's attention to vehicular traffic patterns at street crossings: "I do watch the cars for him. He doesn't watch […] He's so used to the road that he sometimes crosses without looking" (CP06). Problematic encounters in the neighbourhood environment helped heighten care partners' awareness of the outdoor mobility needs of participants. One care partner learned about a participant's difficulty in manoeuvring his walker on unmarked and misaligned (i.e., oriented towards the centre of the street intersection rather than being aligned with the crosswalk) curb letdowns. The care partner realized the importance of providing hands-on support to align the participant's walker with the curb ramp and prevent him from steering his walker towards the edge of the curb, tipping his walker over and losing his balance (see Fig. 5):

> I'm not sure whether it's [P12's] vision that he doesn't actually see the slope, or he just isn't thinking about it. Oftentimes, I have to grab his walker to make sure he doesn't do […] an Evil Knievel over the curb and end up crashing. That happens quite regularly, actually. He forgets to go to the middle of the slope. […] he hit[s] part of the slope of the sidewalk, but he also hit the curb. And so, the walker tipped over. (CP12)

The problems posed by unmarked and misaligned curb letdowns were averted for another participant as a street crossing in his neighbourhood had curb letdowns marked with contrasting yellow tactile strips (see Fig. 6). Seeing the yellow strips reminded the participant to walk towards the curb ramp instead of the curb edge while crossing the street. He explained, "I could see the yellow far away. I know that that's the direction I should go to. Not on the other side where I have to step down. […] if there's no indication […] you're going the wrong way" (P14).

Discussion

Our study underscores the value of the experiential knowledge of people living with dementia to inform UDP-based collective responses to people's out-of-home mobility and participation issues. Understanding the lived experience of walking through the perspectives of older adults with chronic health conditions (e.g., Parkinson's disease, multiple sclerosis, COPD) has been found useful to define previously unconceptualized aspects of walking (Delgado-Ortiz et al., 2023). These aspects of the walking experience include 1) older adults' growing awareness of the need for increased effort, planning, concentration, and adaptation to their environments, 2) needing to generate increased motivation to maintain continued walking and overcome physical and psychological challenges, 3) the link between people's walking experiences, related adaptations, personal meaning and impact, and their sense of self. While Delgado-Ortiz et al. (2023) find similarities in



Fig. 5. *"(Care partner turns walker away from curb edge towards curb ramp) He doesn't always watch when he did this […] He has had an incident, where he's actually tipped the walker"* (CP12).



Fig. 6. *"(Points at yellow tactile strip with cane) You see, they put the yellow in […] Good for me"* (P14).

walking experiences across diverse health conditions and argue for understanding walking experience as a universal concept, rather than in disease-focused and function-centric terms, their study does not include the walking experiences of people living with dementia. Our study findings suggest aspects of walking experience that are unique to people living with dementia, e.g., becoming aware of and adapting to the susceptibility to becoming lost and disoriented, increased need for familiarity and stability in the environment to maintain autonomy and independence in outdoor walking, and increased sensitivity to the cognitive demand of complex and overstimulating environments. More inclusive conceptualizations of walking experience should account for the particular cognitive aspects of outdoor walking for people living with dementia.

Understanding the outdoor mobility needs and goals of people living with dementia based on their lived experience is an important precursor to the development of supportive environments, programs, and services. The study links participants' expressions of AADRC to their attitudes, perceptions, goals, and motivations to maintain outdoor mobility. The findings echo previous research on the importance of mobility in later life to promote capacity, control, autonomy, and freedom, reinforce identity and sense of self, and foster health and well-being (Goins et al., 2015). Musselwhite & Haddad (2018) have found a hierarchical pattern in older adults' awareness of their mobility needs and goals, with 1) the most frequently expressed needs being primary or practical (i.e., ease, safety, and comfort), followed by 2) secondary or social-affective needs (i.e., independence, control, and to maintain roles and identities), and finally, 3) tertiary or aesthetic needs (i.e., sensorial stimulation and exposure to beauty). Consistent with this pattern, participants in our study spoke about adjusting their outdoor walking priorities to mostly meet practical and psychosocial needs. Prioritizing these needs involved being proactive, cautious, and attuned to risk factors in the environment to maintain safety and comfort, realizing the importance of social connection and interdependence, and being in control, exercising autonomy, and maintaining identity. Participants delineated these priorities based on their personal experiences of problematic encounters (e.g., falls, disorientation) following the onset of dementia and realizing the unsupportiveness of the outdoor environment.

Our study findings demonstrate how people living with dementia carry out adaptive processes to negotiate risk factors and meet their practical and psychosocial mobility needs. Participants' definitions of risk in the neighbourhood environment underscored the ways in which they responded to and negotiated risk factors while walking outside, and never as something that deterred them from pursuing outdoor mobility. Perceiving and becoming aware of risk in the outdoors helped participants gain an enhanced understanding of themselves and informed changes in their walking routine to enable them to more effectively pursue their mobility goals. Thus, the study challenges deterministic and reductive discourse surrounding risk that strips people living with dementia of their agency and ability to adapt and respond to intrinsic and extrinsic changes and maintain their outdoor mobility. The findings align with arguments in recent scholarship challenging the prevalence of risk-averse approaches in the provision of dementia care and support (Ward et al., 2022). Exploring the ways in which people define and negotiate risk in the outdoor environment and sustain or constrain their out-of-home activities is useful to identify gaps in the supportiveness of neighbourhoods. Study implications will be discussed along with key points related to participants' primary and secondary mobility needs in the following section.

Linking awareness of changes with outdoor mobility needs

Ward et al. (2021b) call for a relational understanding of the capacities of people living with dementia, emphasizing that interdependence and support are integral to the maintenance of autonomy and freedom. Consistent with this perspective, our findings highlight the role of interpersonal relationships, social connections, and sociocultural norms in shaping participants' AADRC and adaptations. One participant who lived alone alluded to the importance of companionship for her walking routine, the absence of which had led her to abandon walking leisurely in her neighbourhood. The link between perceived importance of physical activity and social connection has also been identified in previous research, wherein meaningful social interaction and emotional support were found to be integral to older adults' satisfaction with physical activity (Meredith et al., 2023).

In terms of the influence of interpersonal relationships, care partners were integral in supporting participants' efforts to adapt to changes in outdoor mobility. Previous research underscores the role of care partners, as well as other community members, in enabling people living with dementia to confidently negotiate risk factors in the neighbourhood environment (Bartlett and Brannelly, 2019; Brittain et al., 2010; Olsson et al., 2013). The case of one spousal dyad showed the participant not just receiving but also providing support to his care partner to achieve joint outdoor mobility. Nelischer et al. (2024) suggest that despite distinctions in the roles of caregiver and care recipient, people can occupy both positions simultaneously. Future research should further explore the reciprocal exchanges of care and support within dyads in the context of out-of-home mobility and participation to produce in-depth understandings of the caring relations of people living with and affected by dementia in urban environments.

Participants discussed how the perceptions of others on the street influenced their confidence to walk alone, and that perceptions of vulnerability were damaging to their sense of safety and security. Bartlett & Brannelly (2019) have also discussed how people living with dementia associate risk (e.g., fear of being robbed or attacked while walking outside alone) with the 'visibility of vulnerability' in the outdoors. Consistent with previous research (Graham et al., 2020), fears associated with vulnerability and safety were more frequently expressed by older women participants in the study, evidencing the interplay of age and gender in shaping mobility in later life (Webber et al., 2010). UDP research should pay closer attention to the gendered nature of socio-spatial relationships of older adults and people living with dementia in the neighbourhood environment (Brüchert et al., 2022). Being perceived as vulnerable by strangers was found to exacerbate our study participants' fears of being attacked and falling, which is consistent with previous research on the environmental factors shaping older adults' fears of crime and falls (Rico and Curcio, 2022). While our study highlights the situational and emergent aspects of vulnerability in the outdoors, it is not aligned with oft-criticized deficit-focused views of vulnerability in older adults and people living with dementia (Grenier et al., 2017). We recommend a closer examination of the concept of situational vulnerability in the context of outdoor mobility to counteract ageist perspectives framing old age or older adults as vulnerable (Langmann, 2023; Shakespeare and Watson, 2018).

Some participants' self-image and body-image (e.g., evidenced by their reactions to the go-along interview video recording) appeared to be influenced by stigmatizing narratives of frailty and dependence associated with late life, disability, and dementia (Grenier et al., 2017). These participants intended to defy these narratives through their efforts to occupy outdoor spaces in normative ways that did not disrupt *place rules* (i.e., socially shared understandings that guide actions in a place to fulfil the place's purpose and denote the roles integral to co-enacting activities in place; Diaz Moore, 2014). For example, one participant spoke about walking faster than her natural pace to cross the street and not be viewed as an imposition by drivers. Previous research has shown that older adults use physical activity to overcome negative stereotypes of aging and match societal expectations surrounding ideal appearance and functioning (Meredith et al., 2023). The question of how communities can be more inclusive and welcoming to people living with dementia, help maintain their dignity, and enable their right to participation, while acknowledging and accommodating situational vulnerabilities, remains to be adequately addressed in research. Strategies to facilitate mobility and participation should centre the '*person with* dementia' (as opposed to focusing on the '*person* rather than the dementia'), recognize both their vulnerabilities and their agency, and adopt an approach rooted in compassion and empowerment (Phinney et al., 2016, p.391). Experiential knowledge based on AADRC is integral to (re)shaping normative conceptions, expectations, and beliefs related to human development (Diehl and Wahl, 2010) and shifting views on mobility in later life beyond narratives of decline (Grenier et al., 2019).

Familiar places in neighbourhoods provided participants with consistent feedback that helped reinforce their AADRC and self-knowledge. Previous research findings suggest that maintaining outdoor mobility in familiar areas promotes a greater sense of control, comfort, and autonomy for people living with dementia (Brorsson et al., 2011). Our findings align with the work of Margot-Cattin et al. (2021) that frames familiarity as an outcome of people living with dementia 'constructing personal territories' (p.9) and continuously negotiating and conducting activities within these territories. Participants' selection of outdoor walking routes in the neighbourhood that meet their need for familiarity reflects their expression of agency and choice in a physical-social context over which they have little control. Selectively walking in familiar settings was framed by participants as a way to rely on their localized knowledge and ability—referred to as 'street efficacy' by Sharkey (2006)—to manage interactions and mitigate problematic encounters. Consistent with recent conceptual work on emplacement (Margot-Cattin et al., 2025), our study findings support a relational understanding of familiarity—not as a pre-existing attribute of places, but as a relationship between people, places, and activity that is experienced and enacted by people living with dementia. A relational understanding demands UDP research and practice to go beyond simplistic understandings of familiarity, in terms of attributes that can be designed into places (e.g., "Familiar streets are hierarchical and long established with forms, open spaces, buildings and features in designs familiar to older people;" Burton and Mitchell, 2006, p.51). UDP research and practice should 1) recognize users (in this case, people living with dementia) not just as passive respondents but as engaged and agentic individuals (Blacksher and Lovasi, 2012), 2) understand how patterns of activity in places are generative of familiarity, and 3) explore how UDP could facilitate the endeavours of people living with dementia to personalize spaces in their neighbourhoods.

Participants' prioritization of familiarity in their outdoor walking routine was also motivated by their awareness (and fear) of the susceptibility to becoming lost, based on past experiences. At its core, getting lost for people living with dementia represents disturbances in their relationship with their surroundings, in their feelings of control and independence, and in continuity of their sense of self (Ward et al., 2022). While most participants' and care partners' response to this awareness was to contain their walks within familiar routes, some participants harboured intentions of walking in less frequented places in their neighbourhood from time to time. This insight suggests that people living with dementia continue to desire diverse outdoor walking experiences but are restricted by challenges posed by the neighbourhood environment. Lloyd & Stirling (2015) suggest that despite experiences of disorientation, the will to be mobile remains intact for people living with dementia, even as their condition progresses. An important question to consider in this regard is how our communities can affirm and support people's desires and motivations to be mobile and allay fears and anxieties triggered by various environmental factors. Participants' anxieties of becoming disoriented and lost were partly attributed to the difficulty of keeping up with fast-paced environmental changes (e.g., loss of features integral to recognizability) they encountered in their neighbourhoods. Previous research has also highlighted the disruptive effects of unexpected environmental changes on people's sense of familiarity and safety (Brorsson et al., 2011; Margot-Cattin et al., 2021). UDP practitioners should recognize the importance of maintaining the stability of the neighbourhood environment and seek the counsel of people living with and affected by dementia in developing measures to retain spatial anchors that are integral to long-standing identities of neighbourhoods currently undergoing changes.

Offering a critical perspective on the freedom of mobility and getting lost with dementia, Ward et al. (2022) raise an important question regarding how neighbourhoods can be more accommodating of experiences of becoming lost, rather than viewing it as a problem that needs to be prevented. Related to this perspective, Brittain et al. (2017) analyze ongoing debates in defining the experience of 'wandering' among people living with dementia, highlighting stigmatizing and

derogatory rhetoric that characterizes wandering as a problematic form of temporality and embodiment. Their study demonstrates that "walking or wandering in dementia is not always aimless or lacking cognitive capacity, but can be linked to memories of familiar places" (p.279). Based on participants' accounts of 'wandering' to familiar places and favourite locations, they argue that people living with dementia have "walking intelligence" that is deeply ingrained in their relationship with the place, thereby challenging stereotypes of "the disappearance of mind and thus of person" that are often linked to 'wandering' (p.281). These approaches run counter to viewpoints reflected in our participants' insights, whereby people living with dementia (and families) are expected to curb or constrain their outdoor movement to prevent becoming lost. Freedom of movement is facilitated more naturally by the culture of small towns and villages, where non-kin-based networks are known to foster support, trust, and belonging for people living with dementia and their families (Bartlett and Brannelly, 2019; Neubauer and Liu, 2020).

Brittain et al. (2017) problematize western cultural connotations of 'walking' as a sign of a healthy mind-body relationship and 'wandering' as a sign of a pathological mind-body relationship, and argue for a cultural shift towards the expanded recognition of expressions of embodied selfhood (i.e., how people express their sense of self through their bodies) and agency among people living with dementia. Expression of embodied selfhood has been found to be critically important to the enactment of social citizenship and how people living with dementia, particularly people who are at a later point in their dementia journey, engage with others (O'Connor et al., 2022). Normalizing embodied selfhood as an integral element of identity, rights, and citizenship has been recommended to challenge the dominant discourse that privileges individual cognition and overlooks the significance of the pre-cognitive and pre-reflective capacities of the human body (O'Connor et al., 2022). Given that autonomous mobility is closely associated with aging in place for older adults (Gibson et al., 2024), expanded understandings of walking that account for the spontaneous and pre-reflective movement of people living with dementia would be valuable to facilitate a dementia-inclusive culture in communities that enhances the quality of people's out-of-home activity and participation and enriches their experiences of aging in place.

Our study findings suggest that the design of the built environment shapes how people living with dementia express AADRC and is integral to their outdoor mobility needs being met, particularly their needs for safety, ease, comfort, control, independence, and balanced stimulation. The findings highlight the role of built environmental features (e.g., visually contrasting tactile strips on curb ramps enabled participants to find a safe path of travel and avoid trip hazards) as cues to reinforce their AADRC. Previous studies have found that some people living with dementia consciously and systematically use different features (e.g., landmarks, signs, public art, street furniture) in the neighbourhood built environment as cues for mobility, orientation, and wayfinding (Blackman et al., 2007; Brorsson et al., 2011; Burton and Mitchell, 2006; Olsson et al., 2013; Seetharaman et al., 2020). However, living with dementia presents difficulties with memory (e.g., recalling the presence/location of certain features) (Gresham et al., 2019) and parsing surplus stimuli to find relevant cues (Brorsson et al., 2011, 2016; Rosenkvist et al., 2010). Interpreting and using cues can be challenging, especially when they are poorly designed (e.g., a sign that is located too high or too low, overcrowded with information and difficult to comprehend, and has poor contrast), which in turn has been found to negatively impact the perceived accessibility of the environment among people living with dementia (Brorsson et al., 2011; Burton and Mitchell, 2006).

Our findings further reinforce the relevance of consistent, noticeable, and legible environmental cueing by highlighting how inadequate environmental design and maintenance could hinder people's awareness of risk in their neighbourhood environment, result in unmet outdoor mobility needs, and compromise the quality of outdoor walks in the neighbourhood. Future research should further examine how environmental cueing could be augmented to enhance the cognitive accessibility of streets and outdoor public spaces, through an in-depth examination of characteristics of environmental features relevant to people living with dementia, e.g., complexity, visibility, noticeability, identifiability, and recognizability.

Adopting an 'ethic of care' is necessary to realize institutions, infrastructures, and community spaces that facilitate caring practices between individuals and value the equal distribution of care (Nelischer et al., 2024). An important question for future research is how local government, non-governmental sectors, and communities can conceive of alternative ways to facilitate mutual care and support in urban neighbourhoods, i.e., repositioning care as a public concern and spaces in cities as sites for "collective interdependence and mutual responsibility for care" (Nelischer et al., 2024, p.4). Beyond standalone intervention-based built environmental measures, meaningfully addressing challenges to orientation and wayfinding in outdoor spaces calls for a broader change in society's views and assumptions on diverse mobilities, which in turn influence the social, political, and material contexts in which mobilities are sustained or hindered. This culture change requires dementia research, policy, and practice to steer clear of generalizing and standardized framings of dementia and adopt place-based approaches that highlight the relational, situated, and heterogeneous nature of lived experiences of dementia (Chaudhury et al., 2024).

Study limitations

The study is limited to the experiences of people with mild to moderate dementia and does not focus on people who are further along in their dementia journey and living in the community. Future research should include the lived experiences of people living with moderate to severe dementia and their care partners to more holistically explore patterns of awareness and coping in the context of outdoor mobility. Biglieri and Dean (2022) have recommended expanding research on how multiple chronic conditions and disabilities shape the outdoor mobility experiences of older adults. The findings of our study reflect how comorbid health conditions (e.g., osteoarthritis, stroke, Parkinson's disease) shaped the experience of walking outside for people living with dementia; however, the influence of comorbidities was not systematically explored. Purposive sampling could be employed in future research to account for different comorbidities in the study of outdoor mobility of people living with dementia.

The study focuses primarily on outdoor mobility, and more specifically, walking in the neighbourhood. However, people's relationships with their neighbourhoods are not defined solely by walking outside and involve participation in a wide range of activities in different settings. Recent studies have examined the influence of the physical and social environment on a range of out-of-home activities that community-dwelling people living with dementia participate in (Brittain and Degnen, 2022; Brorsson et al., 2020). Future research should continue to examine person-environment relations in different activity settings and how they impact community participation for people living with dementia.

Conclusion

This study explored the interplay between AADRC, motivations for outdoor walking, and perceptions of the neighbourhood environment through the lens of the experiential knowledge of people living with dementia. Our findings reflect participants' heightened awareness of risk factors in the neighbourhood and the need to implement adaptations in their out-of-home activity routines to maintain their pursuit of mobility-related needs and goals. We do not suggest that AADRC and related adaptations are the sole determinant of participation in out-of-home activity, nor do we wish to inadvertently contribute to the issue of responsibilization by framing mobility and social participation as the

sole responsibility of the person living with dementia or their family member. AADRC is used as a conceptual tool to understand the cognitive processes of how people make sense of dementia-related changes and use self-knowledge to adapt to the environment to maintain out-of-home activity. UDP can be better informed by the lived experiences of people living with dementia through nuanced understandings of their spatial needs and requirements. UDP policy and practice should take better account of the vast diversity of out-of-home activity needs and experiences of citizens. Understanding the experiential knowledge of people living with dementia is crucial to augmenting the accessibility and inclusivity of neighbourhood environments.

Ethics statement

Ethical approval for this study was obtained through Research Ethics BC Network from Simon Fraser University and the University of British Columbia (H21–03552).

CRediT authorship contribution statement

Kishore Seetharaman: Writing – review & editing, Writing – original draft, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Habib Chaudhury:** Writing – review & editing, Supervision, Funding acquisition. **Lillian Hung:** Writing – review & editing, Funding acquisition. **Atiya Mahmood:** Supervision. **Alison Phinney:** Writing – review & editing, Supervision. **Richard Ward:** Writing – review & editing, Supervision.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

This work was supported by the Alzheimer Society of Canada (2020 Alzheimer Society Research Program Policy and Health Systems Change Doctoral Award [#21–21]), Mitacs (Accelerate Internship), and Public Health Agency of Canada (Dementia Strategic Fund: Awareness Raising Initiatives)

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