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'We have different routes for different reasons': Exploring the purpose of walks for carers of people with dementia

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Abstract

This paper explores the purpose of walks for co-residing carers of people with dementia, using a social citizenship lens. The findings are based on the first phase of a study examining the everyday experiences of place, space, and neighbourhood of dementia carers. Using three forms of data collection – social network mapping, walking interviews, and participant-driven photography – the study brings forth information about why carers go on walks either alone or with the person with dementia. Carers explained that walks facilitate their connections with themselves, the person with dementia, their social environment, and their natural and built environment. In sum, walks provide a way of practicing and sustaining social citizenship. Carers' discourse about walks highlights their personal, everyday practices and strategies, as well as the larger tensions and contradictions of dementia care. The findings reinforce the need to bring into dialogue, from a carer perspective, a social citizenship model of dementia with the growing interest in dementia-friendly communities.

Keywords

carers, dementia-friendly communities, neighbourhoods, walking, social citizenship

This paper aims to understand the purpose of walks for family carers of people with dementia, using a social citizenship lens (Bartlett & O'Connor, 2010). Drawing on findings from the first phase of a study exploring the everyday experience of place, space, and neighbourhood of dementia carers, the paper sheds light on how walks facilitate the practise of social citizenship. Based in part on walking interviews with carers in their neighbourhoods, the findings reveal that walks are vital to carers' connections to their

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relational, social, and physical environment and that these connections are in turn central to the practice of social citizenship (Bartlett & O'Connor, 2010). As I elucidate in the discussion, walks can thus be seen as personal acts of resistance against possible social death (Sweeting & Gilhooly, 1997). Throughout the paper, I rely on Bartlett and O'Connor's (2010) definition of social citizenship, yet I extend it to carers, illustrating that they, too, are seeking agency, fulfilment, social purpose, and stigma-free connections.

In recent years, there has been a growing body of scholarship pertaining to the concept of dementia-friendly communities (Bartlett, 2016; Mitchell, 2012). This literature has highlighted the intersections between the social and built environment and the ways in which communities are supporting the personhood and citizenship of people with dementia. There has also been a parallel trend in citizenship studies to emphasize the contribution of the domestic home environment to the practice of social citizenship (Baldwin & Greason, 2016). The current study brings together these trends and extends the theorizing of dementia-friendly communities and social citizenship to carers, using walks as an applied example. From the perspective of the carer, it takes up Bartlett's (2016) call for dementia-friendly communities to become a forum for applying the multifaceted aspects of a social citizenship model of dementia.

Throughout the paper I address walking as both a verb and a noun. While the act of walking itself is implicit, the paper is primarily about 'walks' and their meanings for carers of people with dementia. Using a social perspective and a critical lens, my use of the word 'walk' as a noun includes actions as diverse as being out in the community with mobility aids as well as stepping forward on two feet.

The paper begins by contextualizing the topic in the broad literature on the social and cultural dimensions of walking. While there is a vast interdisciplinary literature regarding the multifaceted aspects of walking, as well as literature exploring the intersections of walking and dementia, there is little scholarship that has theorized walking in conjunction with caring for someone with dementia. What purpose do walks serve for carers? What does it mean for carers to go on walks? Through a discussion of the early findings from the current research, I address these questions on two levels – the personal, subjective experience of the care partner and the social context in which they are providing care.

Background

Walking as a concept as well as an act 'trespasses through everybody else's field' (Solnit, 2000, p. 4), extending through disciplines as diverse as cultural studies, urban planning, and human geography. There is agreement that walking is much more than a functional act. The way that people walk and where they go are affected by seasons and weather, disciplined and regulated by city by-laws, and determined by history and culture (Edensor, 2010). Walking can be an act of resistance (Solnit, 2000), an act of transgression (Morris, 2004), a means of having significant social encounters (Middleton, 2016), or a way of creating or transforming place through acts of improvisation and creativity (Butler, 2006; de Certeau, 1984; Pink, 2008). Walking is also linked to memory, as we recall places, topography, sounds, and feelings of familiarity (Butler, 2006). Like Wunderlich's (2008) concept of discursive walking during which one roams and follows one's internal rhythm, the liberty to be a *flâneur* (Tester, 1994), or to let oneself *dérive* (Debord, 1956), highlights the ways walking can elicit creativity, memory, history, and identity.

Despite the broad links between walking, memory, and identity, there is only a small amount of literature that has brought these concepts together with dementia. Recently, Phinney, Kelson, Baumbusch, OConnor, and Purves (2016) found that for people with dementia, group walking was a way of creating a sense of social belonging and of claiming space in the community, hence practising social citizenship. Previous literature has emphasized that outdoor activities can reinforce self-worth, identity, and social inclusion in people with dementia (Duggan, Blackman, Martyr, & Van Schaik, 2008; Olsson, Lampic, Skovdahl, & Engström, 2013) and that physical activity can be a way of preserving links with the past (Cedervall, Torres, & Aberg, 2015). Unlike studies focused on the role of walking and physical activity in preventing, slowing, or mitigating the effects of dementia (Aarsland, Sardahaee, Anderssen, & Ballard, 2010; Calkins, Szmerekovsky, & Biddle, 2007; Kemoun et al., 2010), the scholarship mentioned above elucidates the importance of walking in maintaining the agency and selfhood of people with dementia.

People with dementia nonetheless face numerous restrictions to going on walks outdoors. They often experience a shrinking geographic comfort zone due to barriers in the built environment, social stigma, reduced confidence, and increased anxiety (DeWitt, Ploeg, & Black, 2009; Duggan et al., 2008). While they may develop strategies for getting around outside and thus for preserving independence – such as using landmarks or going to familiar places (DeWitt et al., 2009; Mitchell & Burton, 2006) – walking is often perceived as risky. Managing risk and focusing on personal safety have become primary elements in informal and formal care for people with dementia (Bailey et al., 2013; Clarke et al., 2011). Going out can become a 'contested territory' (Clarke et al., 2010), as people with dementia are often not permitted to roam, wander, or go out alone, for fear that it will lead to getting lost (Rowe et al., 2011; White & Montgomery, 2015). Unlike the *flâneur* who can meander or get lost for the sake of creative pleasure, in the case of people with dementia, wandering and getting lost can often lead to further restrictions or to institutionalization (McShane et al., 1998).

The links between walking, identity, and the outdoor world have only been extended to the carers of people with dementia in a limited way, often in regards to how physical activity can improve their health and well-being (King & Brassington, 1997). Yet some pioneering work has moved beyond a health perspective into an exploration of carers' experiences of place and space. Janine Wiles (2003) illustrated that carers (caring for someone with any illness, not only dementia) experience a shifting sense of space, place, and time in relation to their indoor and outdoor worlds. This was later echoed in the work of Daly et al. (2012), who elucidated how dementia carers' worlds shrink along with the person for whom they are caring and how they also face stigma and changes in their social relationships. More specifically, a UK-based study by Ward, Clark, and Hargreaves (2012) examined how carers made use of their neighbourhoods both socially and physically, and found that carers placed great importance on social contact as a means of maintaining their own identities and independence. While not linked to walking per se, this literature reinforces the need for further examination of the links between dementia care and the world outside the home.

Description of the study

The project's main objective is to understand how dementia carers perceive, experience, and engage with the physical, social, and emotional elements of their neighbourhood. Guided by the question *What are the everyday experiences of place, space, and neighbourhood of co-residing carers of people with dementia?* the research interrogates how carers feel about their neighbourhoods, where they spend their time, and how they are supported locally. Aligned with recent trends in the social sciences to access the multi-sensory elements of the research environment (Hurdley & Dicks, 2011; Knoblauch & Tuma, 2011; Pink, 2015, 2011; Ward, Campbell, & Keady, 2014), the current study employs a mix of social network mapping, walking interviews, and participant-driven photography. The project adheres to Canadian Tri-Council guidelines (Canada Public Works and Government Services, 2005) and has ethics approval from the University of Ottawa.

I recruited participants through a community-based organization in Ottawa, Canada that specializes in services for people with dementia and their carers. During the first phase of the study, on which the current findings are based, I interviewed six carers ranging in age from 54 to 68. The persons for whom they were caring ranged in age from 63 to 90. Deborah, Maureen, and Janet were caring for a parent, whereas Sylvia, Doug, and Albert were caring for a partner (all names have been changed to protect confidentiality).

During the first interview, which took place in the participant's home, I gathered information about the carer's overall situation and together we created a map of their social networks. To create the map, I gave the participants a large piece of blank paper and markers and asked them to write down the names of the people with whom they communicated or interacted in a typical week, whether family, friends, neighbours, or businesses. This network mapping technique, used in research that attempts to capture people's experiences of their networks and communities (Emmel & Clark, 2009), elucidated the broad scope of participants' social connections and the ways in which these connections were linked to their everyday living patterns. During the initial interview, I also loaned each participant a camera and instructed them to take 12–15 photographs of places, spaces, or objects in their everyday lives.

The second interview consisted of a walk in the participant's neighbourhood, on a route of their choosing. The walks ranged in duration from 30 to 90 minutes and the locations varied from snowy country paths to sunny residential or urban streets. In addition to audio-recording the interview, I took photographs of visual markers and tracked the route with a GPS app in order to provide visual accompaniment to the transcripts. These mobile interviews immersed me in the local, dynamic environment of the participant (Carpiano, 2009) and provided concrete understanding of how the participant used and moved around in their neighbourhood (Emmel & Clark, 2009). Whereas the social network map addressed the carer's broad community of support, whether near or far, the walks focused on the carer's experience of their local environment.

During the final interview, again in the participant's home, I elicited discussion based on the photographs taken by the participant. The carers' images were varied, including household objects, parking lots, nature trails, shopping centres, and swimming pools. Like the social network maps and walks, the participant-driven photography brought forth unique information about what the participants considered meaningful in their everyday lives (Clark-Ibanez, 2004; Harper, 2002).

I analysed the network maps and photos in much the same way as the interview transcripts, by winnowing the raw and partially processed data into initial meaning units or codes and then developing these codes into preliminary concepts and finally into principal themes (Creswell, 2013; Pagdett, 2008). Adopting a self-reflexive stance was extremely important for my overall understanding of the material and the ways in which the data was co-constructed (Pink, 2008). In order to deliberately integrate the ways in which my own sensory experiences contributed to the overall understanding and sense of place in each environment, I remained aware of sounds, sights, smells, and feelings during the interviews. After each interview, I wrote extensive field notes, in order to keep the visceral details present and active during the analysis.

Findings

Although participants talked about going on walks for instrumental reasons, the findings extend the purpose of walks beyond simply getting from Point A to Point B. The participants expressed that walks were multipurpose, operating on both personal and social scales. In particular, walks facilitated various types of personal and public connections, essential to the practice of social citizenship.

Dyad connections

Participants talked about walking with the person with dementia as a means of sustaining, improving, or managing the dyadic relationship. Going on a walk was described as a mechanism for managing tensions, helping with transitions during daily routines, or resolving or preventing distress on the part of the person with dementia. In these instances, going outside with the person with dementia acted as a tool for easing moments of high emotion. It became a strategy for reducing stress on the part of the person with dementia and by consequence on the part of the carer. The diminished stress in turn helped improve the overall connection of the dyad. For example, Maureen, who is caring for her mother, explained:

> *We have different routes for different reasons. Sometimes it's just to – I call it – to take the lid off the pot . . . Mom loves to go outside to walk. She loves to go on rides. She loves to go outside, period, all around. She needs to go outside so we have been doing this walk through all seasons, through all-weather types.*

Maureen's description of walks as a way to 'take the lid off the pot' speaks to the tensions that are part of her everyday life as a carer to her mother. They encapsulate the underlying emotional labour of daily, co-residing caregiving. Yet in addition to highlighting these tensions, her words also point to the ways in which walks are used as a strategy for alleviating tensions.

In addition to being a method for maintaining emotional and relational harmony, walks also served as an activity of togetherness. Walks and outings were described as ways of engaging in meaningful time together when other activities may no longer be possible. For example, Maureen expressed that while on walks with her mother, they '*always have such a nice time together*'. She further illustrated this with a photograph of her and her mother arm in arm. The linked arms provide a poignant visual of their sense of togetherness while out on walks.

Similarly, Sylvia talked about walking with her husband as a means of exchange and a time for simply being together. She described how walks facilitate moments of discussion – '*A lot of* *what we talk about as we walk is what we see in terms of gardens and plants and birds and things like that*' – as well as sharing times of calm connection:

> *Well, we often walk through the park and it's a place that is – it's always calming. We often will go up onto the soccer field in the summer – well, spring, summer, fall – if he wants to look at constellations and stuff like that. It's just a nice place to be.*

Walks are thus expressed as ways of maintaining closeness and togetherness in the dyadic relationship, or as ways of calming tensions in order to be able to reconnect and re-establish a sense of harmony in the relationship. As such, walks reinforce one of the principal aspects of social citizenship, that of engaging in relationships that enable growth (Bartlett & O'Connor, 2010).

Social connections

In addition to facilitating connections in the dyad, walks were referred to as a means of sustaining or developing social interactions in the community. Reflecting Ingold and Vergunst's (2008, p. 1) statement 'not only...do we walk because we are social beings, we are also social being because we walk', the participants explained that walks were highly social acts, both for themselves and for the person with dementia. Deborah explained how going on walks helped her feel connected to what is going on in the neighbourhood:

> *There's lots of moms getting their kids off to school here, kids traveling on their own, people scurrying off to work – just a busy kind of atmosphere until you get to the lake. you see a lot of fellow dog owners so it becomes a bit of a social event.*

Deborah articulated her appreciation of the informal nature of the social interactions that occur during walks. She could choose to talk to someone or she could choose to remain solitary. As she stated, '*It's connecting without having to have a real commitment. It's just very serendipitous. Whoever shows up is there*'. A crucial aspect of the social connection is simply seeing others and being seen in return. The people along the way are familiar and can be approached or not depending on her mood. As Deborah stated, '*If I don't want interaction, I just walk faster ... If I'm not in the mood to chat too much or if I've got other things on the go, I still get my walk in*'. Even without direct social contact, a walk still offers a contrast to the invisibility that many carers feel as their identity is submerged in their caregiving role. According to Deborah, '*it's such a contrast to the one-on-one time that I do with my computer or that I do with my mom. It's getting back out there – seeing people, connecting*'.

The participants talked about the presence of the person with dementia as a facilitator of social connection. Maureen stated that walking in the neighbourhood with her mother increased her contact with the neighbours and encouraged social interactions that had not existed prior to her mother's decline. The fact that her mother says hello to everyone and often hugs them compels interactions that would not have occurred otherwise. According to Maureen: '*It's nice to say hello to the neighbours. In fact, I've gotten to know some of my neighbours more with Mom as opposed to without Mom for that reason because she will seek out*'.

The participants were emphatic that the social aspect of walks was equally as important for the person with dementia. Doug described the importance of social connection for his wife: '*She likes to walk in neighbourhoods where there's people...Social contact is very* *important . . . She's very social and a sociable person*'. Similarly, Maureen talked about the vital importance of social connections for her mother:

> *I think Mom loves the outings because it's social contact. It's fresh air and I mean for multiple reasons Mom loves being outside and the social contact with people is a must. She will draw people into her – into her world – whether if we're in the car, she's madly waving to the driver. Oh, seriously. She might even roll her window down if she remembers how to do that or elicit me to do so.*

The participants also articulated the importance of experiencing non-stigmatizing social connections while on walks. For example, Maureen talked about the many neighbours who have come to know and accept the hugs from her mother and the relief she feels at their understanding. While one's history in a particular neighbourhood can often facilitate such non-stigmatizing connections due to familiarity (Clarke & Bailey, 2016), for the participants, history was not a guarantee of acceptance. For instance, Janet explained that certain long-standing neighbours and friends had pulled away as her mother declined, echoing previous research that demonstrates that while friendships can be a vital source of support, friendships can also be difficult to maintain post-diagnosis (Ward, Howorth, Wilkinson, Campbell, & Keady, 2012). As I elucidate in the discussion, the participants' descriptions of their social and community connections indicate that they receive support from a complex variety of sources, both old and new, and that walks encourage the development of these connections.

Environment connections

In addition to the social and relational connections that walks reinforced, the participants expressed that walks facilitated their connections with nature as well as with the built environment of their neighbourhood. Similar to Wunderlich's (2008) conceptual mode of walking in which one learns and discovers an environment, going on walks allowed carers an opportunity to witness changes and uncover patterns. They commented on the enjoyment they received from observing their natural surroundings, in particular the changes that accompany each season. The following comment from Sylvia illustrates this enjoyment:

> *Lots of geese. Sometimes it's fun when this time of year – when the geese are coming back, or in the fall and you get lots of them flying in V's. You'll look up and they'll be – gulls try to fly in V's and it's really quite amusing.*

For Doug, being outside was a way of retaining his connection with the outdoors, a long-standing component of his life: 'We lived in the woods, in the rural property . . . I used to go hiking all the time . . . you know finding this park land and a little bit of topography was quite enjoyable'.

Echoing research that found that witnessing the changing environment is important for the well-being of people with dementia (Clarke & Bailey, 2016), the participants emphasized the importance of nature for the person with dementia, whether facilitated through walking or another activity such as gardening. For example, Janet underscored the importance of the garden for her mother: '*That's the garden . . . . that's the one area of competence that Mom really hasn't lost . . . .She's out morning to night in the nice weather*'.

Weather played a large role in mitigating participants' relationships to their environment. They explained how their ability to be outside was significantly reduced during the winter months. Weather affected both where they chose to walk (i.e. which path they took), as well as the length and frequency of the outings. Sylvia, in talking about the choice of location, stated: '*At times you have to be careful. Like last week it was even icier under there, but now it looks as though it's not too bad*'. Maureen talked about how bad weather also affects the duration of the walks: '*For certain if it was a weather factor consideration, we would not take this route. This is the longer route, so we would just go on a little short one*'. Despite the reduction in time outside or the changes in the route, walks remained an important part of their routine, even in winter months.

The importance of observing changing patterns was mentioned not only in relation to the natural environment but to the social and built environment as well. Walks allowed participants to recognize the neighbourhood's patterns, for example, what people were doing at various times of the day and the evolution of the social and physical space over time. Doug commented:

> *You don't see it right now because of the weather, but come summer the streets are full of kids playing on the streets, which we haven't seen in a long time... But there'll be basketball nets, hockey nets, ball gloves – the streets are just full of kids and the residents here – the people driving the streets – are very good about it.*

Walks, therefore, facilitated the dyad's awareness of their surroundings, as well as encouraged their participation in their environment as social agents.

Self-connections

Complementing the connections to their relational, social, and physical environment, carers also spoke of going on walks, either alone or together, as a strategy for maintaining identity, both for themselves and for the person with dementia. For Deborah, walking alone was expressed as a way of taking time for herself: '*It's an important part of my day. It kind of resets things.... Puts new perspective on life....A mini-vacation*'. The walks were also a way of focusing on something unrelated to caregiving:

> *I'm actively seeking other things other than – because I'm not just a caregiver... Well, yeah, I am a caregiver, but not just a caregiver.... I make it to the gym every day and I do yoga. And my walks are for me. I make time for myself. And my evening activities – I get out twice a week. So those are for me.*

Yet Deborah articulated that it is difficult to maintain her own activities, due to the time limitations that caregiving imposes. She described how she tries to work around these limitations:

> *Well, the walks have always been part of my life since we've had the dog, so for the past 13 years an hour walk a day has been standard. The timing has changed. I have to work it around having someone available to care for her, so that means either I go before there's any chance she's up or I go when there's a care provider available for me. So I sort of juggle that time a bit.*

Maureen echoed the need for activities for herself, yet the simultaneous constraint of time pressure:

> *Well, I can't just up and go running on my own because now... it's returned to – oh, I can't go do that and I can't go out to exercise. I'm going to get it incorporated now that I've got this little batch of respite care.*

Carers also talked about the role of walks in maintaining the identity of the person with dementia. In addition to relational, social, and environmental connections, the carers tried actively to maintain their partner's or parent's links to self-continuity through walks. For example, they described the ways in which walks supported their memories and past interests. Maureen described how she often took her mother on a route where they would see school children, since this reminded her mother of being a school bus driver. The walk thus reinforced an intrinsic aspect of her mother's identity:

> *If it's morning time we'll see children on their way to school. If Mom is drawn to the school children and the sight of buses usually – because Mom used to be a school bus driver, so she enjoys that, seeing the children and the school bus. So then we'll go to the school route, which is coming up – up ahead.*

Participants spoke more generally about the ways in which walking outdoors had often been important throughout the life of the person with dementia and therefore something they wanted to preserve. Deborah explained:

> *When my mom was able to walk around, she used to like it because she grew up in the country or in a smaller town, anyway .... So I think just having a lot of trees and the water was calming for her.*

Walks were articulated as a means by which to maintain the autonomy of the person with dementia and by consequence their identity. For example, Maureen talked about letting her mother choose the route:

> *This is actually a route that she chose herself, just on one of the days where we just set off and said well, let's go for a walk, Mom. And we went up the hill, so this is the "up there" – this is what she calls.*

Similarly, Sylvia talked about wanting to let her husband take the lead for as long as possible: '*I'm still getting him mostly to lead the walks because he hasn't – he still doesn't get lost that way ....But in this area he doesn't get lost, so I wanted to keep him doing that as long as we can*'.

Yet letting her husband take the lead was also a way of checking that he still knew where he was going. The desire to support his freedom collided with worries about his safety. Despite her worries and the doctor's concern, she continued to encourage her husband to go for walks alone in areas where he still felt comfortable. She stated:

> *When he was first diagnosed, the doctor made me believe that he was going to be lost ... and I'm thinking no. And the first few times I went to aquafit and he came to meet me ... he came on his own and I wasn't there ...*

Despite anxieties and adaptations, the carers nonetheless forged ahead with walks. If there were no sidewalks on a particular street, or if the sidewalks were covered in snow, Doug walked in the middle of the road with his wife, feeling confident that cars would stop. He also continued taking his wife on long walks in the woods, down steep and potentially dangerous staircases, and along snowy terrain. Albert, who had put what he called a 'dog tag' on his partner, accepted that his partner would get lost from time to time. In the following statement, he explained what happened when his partner went out one morning and didn't come home. His reaction attests to both his worry and acceptance:

> *When he hadn't returned by 10:00 ... I said yes, he's definitely lost. And I realized ... the futility of going out to find him because he could be on any one of those streets or he could be inside*

> *a restaurant. But not too much anxiety because I said I knew that sooner or later someone would phone, that he would either be found by someone saying "Can I help you?"*

Simply having the will to maintain their own identity and autonomy – and that of the person with dementia – did not make this an easy endeavour. It required deliberate acts that were often fraught with tensions. These tensions, as discussed below, reflect the challenges of the everyday practice of social citizenship.

Discussion – Practicing social citizenship through walks

As illustrated in the findings, walks offer an applied example of the everyday practice of social citizenship for carers of people with dementia. The purpose of walks for the carers in the study aligns with the foundational elements of Bartlett and O'Connor's (2010) model of social citizenship in a dementia context: engaging in opportunities for growth, maintaining identity, having a sense of purpose, participating in the world as a social agent, retaining a sense of community, and enjoying freedom from discrimination. Each of these components emerged as important in the participants' discourse about walks, illustrating the relevance of extending a social citizenship model of dementia to carers. Going on walks, either alone and/or with the person with dementia offered the carers in the study a means of growth and connection with the person with dementia, a way of retaining their identity beyond the caregiving role, and a means of engaging purposefully in their community. The participants also emphasized the ways in which they attempted to maintain these elements for the person with dementia.

The findings reveal that walks encapsulate the tensions and contradictions involved in the everyday practice of social citizenship in the context of dementia care. In addition to managing numerous barriers to going on walks both alone or with the person with dementia – inclement weather, road or sidewalk conditions, time limitations – getting out of the house means that the carer must simultaneously engage with the broader contradictions involved in the practice of social citizenship. For example, the carer's need for togetherness and connection is counterbalanced by a yearning for solitude and respite; the carer's desire that the person with dementia retains autonomy and independence draws attention to a parallel anxiety about their safety; the carer's wish to claim space in the community for themselves and for the person with dementia is accompanied by a vigilant awareness of possible stigmatization. These contradictions, which emerged through the discussions about walks, reflect the broader tensions of dementia care, in particular the struggle for each member of the dyad to preserve their personal and social roles.

Although walks bring to the fore the above-mentioned tensions they likewise offer a response. The carers characterized walks as opportunities for repairing or preserving their sense of self through social, familial, or environmental connections, as well as for building new associations. As is the case with Maureen, who met new neighbours as a result of her mother's dementia, walks offer carers an avenue for building new social capital. Reinforcing research that has illustrated the positive impacts of the cultivation of neighbourhood social capital (Carpiano & Kimbro, 2012; Cramm, Van Dijk, & Nieboer, 2013; Forsman, Herberts, Nyqvist, Wahlbeck, & Schierenbeck, 2013), the carers expressed the importance of preserving their participation and connection in the social sphere beyond the home. The fact that this participation in the world outside the home – a key component of the practice of social citizenship – can be sustained and grown through activities such as walks, attests to the fact that agency, community, purpose, and growth are important and possible even in the context of dementia.

The need to participate in the world and to experience new things is at the heart of walking itself (Solnit, 2000). Part of the beauty and enjoyment of walking is getting lost, for instance lost in a city, lost in thought, lost in discovery, or lost in reverie (Ingold & Vergunst, 2008; Solnit, 2000). The findings reveal how both the carer and the person with dementia are seeking such a journey. Both are attempting to safeguard their sense of agency. Despite limitations, walks are one way in which they are exercising these needs, even when confronted with structural barriers, difficult weather, or doctor's warnings, or potential stigma. Walks can thus be seen as acts of resistance against the loss of self and a shrinking world (Duggan et al., 2008). While historically walks have been associated with acts of transgression or manifestation (Solnit, 2000), in the case of carers these are small, daily, personal acts of resistance. These personal acts of resistance, which may not be named as such, nonetheless offer a way of practicing, and of claiming, social citizenship.

Conclusion

This paper has interrogated the purpose of walks for family carers of people with dementia and has thereby illustrated how walks provide an applied example of the practice of social citizenship in everyday life. It has elucidated the necessity of extending a social citizenship model of dementia to carers, especially in the context of the growing movement towards dementia-friendly communities.

The findings confirm the need to bring together carers' realities both inside and outside the home. The carers in the study expressed the links between the home and the outside as being intrinsic to their sense of self. They elucidated this in their articulation of the need for connections with the person for whom they are providing care, as well as with their natural and social environment. Walks offer a way of fulfilling these needs, as they bridge the personal and the social, and place the carer's private reality into dialogue with the public sphere. As such, walks are a personal, micro-level strategy for managing the everyday realities of dementia care; yet they also offer a public response. They are personal acts of resistance that reflect an assertion of citizenship in private and public spheres. The carers are claiming a multifaceted life, for themselves and for the person with dementia, even in the face of significant change and challenge. Going on a walk is an everyday act that offers a commentary on how carers – and the people for whom they are caring – are continuing to exercise social citizenship.

This paper has addressed only one aspect of the practice of social citizenship, namely the experience and purpose of walking in one's neighbourhood. It is clear, however, that carers' connections extend far beyond their local neighbourhood and into a larger community of family, friends, services, and businesses, both concrete and virtual, local and distant. A pertinent next step, especially in the context of dementia-friendly communities discourse, would be a dialogue that articulates how carers' broader communities facilitate their practice of social citizenship.

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