

Walking in the Neighbourhood: Performing Social Citizenship in Dementia

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ABSTRACT

The proliferation of community-based activity programs for people with dementia suggests an appetite for new approaches to support quality of life and well being for this population. Such groups also have potential to promote social citizenship, although this remains poorly understood. This article presents findings from a subset of data from an ethnographic study of a community-based program for people with young onset dementia; it focuses on Paul's *Club* and the experiences of 12-15 members who are physically healthy, with moderate to moderately severe dementia. Analysis suggests how aspects of social citizenship are constructed and revealed through the Club's everyday practice of walking in the neighbourhood. Three major themes emerged: *Keeping the focus off dementia*; *Creating a place of belonging*; and *Claiming a place in the community*. How the group balances consideration of members' vulnerability and agency is discussed, and the article concludes with implications for future practice and research initiatives.

INTRODUCTION

Community-based activity groups for people with dementia are burgeoning in Canada, the UK, and beyond. Many are grassroots efforts that are emerging outside the institutionalized contexts of health and social care. For example, *Dementia Adventures* in England arranges outdoor activities and adventure holidays for people with dementia and their families in order that they can “live well with dementia and have a sense of adventure in their lives” (Mapes & Hine, 2011). The *Culture Bus* in the US provides opportunities for people with early stage dementia to visit cultural sites and community events with the aim being “to challenge the senses, inspire imagination and expand knowledge about ourselves and the world” (Partners for Livable Communities, 2012). Programs such as these are variously organized under the broad umbrella of community services and comprise a diverse range of activities. Whether it be Singing Groups in Scotland (Osman, Tischler & Schneider, 2014), Dinner Clubs in Canada (Cassolato, Keller, Dupuis, Schindel-Martin, Edward & Genoe, 2010) or Men’s Sheds in Australia (Brown, Foley, Harvey & Gleeson, 2007), taken together these kinds of groups represent a potentially important shift in how society understands and responds to dementia.

To begin, it is a move away from an emphasis on behavior and function to acknowledge the importance of well-being and quality of life for those living with the disease. Studies have shown that physical, creative and leisure activities can have significant benefits in this regard (e.g. Genoe & Dupuis, 2014; Parisi, Roberts, Szanton, Hidgson & Gitlin, 2015; Phinney, Chaudhury & O’Connor, 2007; Potter, Ellard & Thorogood, 2011; Zeilig, Killick & Fox, 2014), and there is emerging evaluative evidence that community-based activity groups are a way to bring pleasure into people’s lives while helping them sustain important social connections and a

sense of personal identity (Davies-Quarrell et al., 2010; Hampson, 2009; Kinney, Kart & Reddecliff, 2011; Phinney & Moody, 2011). Our purpose in this article is to take the analysis a step further to explore how community-based activity can potentially support *social citizenship*, which we understand as “a relationship, practice or status in which the person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible” (Bartlett & O’Connor, 2010, p.37). Various scholars have identified the importance of social citizenship for people with dementia (Bartlett & O’Connor, 2007; Baumbusch, 2008; Behuniak, 2010; Cantley & Bowes, 2004; Gilmour & Brannelly, 2010; Milne, 2010), and there is increasing interest in developing policies and guidelines for better supporting people with dementia as active and engaged citizens (Whitfield & Wismer, 2006; Williamson, 2012). However there has been very little work done to examine the potentially important role of community-based activity groups in supporting social citizenship. That is the purpose of the research we are describing here. Drawing on the conceptual work of Bartlett and O’Connor, we are examining the question of how these kinds of community-based activity groups might create opportunities for social citizenship, specifically in terms of the following aspects: growth, purpose, participation, community, social position, and freedom from discrimination (2010, p.40).

Toward this end, this article presents findings from ethnographic research that we have conducted with Paul’s Club, an innovative social activity group for younger people with dementia. We begin by describing the group’s structure and operations, and then go on to discuss how this group demonstrates the potential of *walking in the neighbourhood* as a

practice that constructs social citizenship of people with dementia through shared engagement in social activity.

Paul's Club

Paul's Club is an independent social recreation group for people who have young onset dementia. While this group has no formal connection with the health or social care system, most of the members are referred through a memory clinic at a large teaching hospital, with others arriving through word of mouth. The group is supported through membership fees, with additional funding coming through a variety of fundraising efforts. Paul's Club is located in the city of Vancouver, Canada, and is organized as a social enterprise with members paying on a sliding scale to attend anywhere from one to three days a week from 10 am-4 pm. Members come from Vancouver and its adjoining communities, travelling to and from the club using a publically funded door-to-door transit service. There are three full time leaders, one of whom is a certified recreation therapist, and a pool of approximately 15 volunteers (referred to as "friends") two or three of whom come each afternoon to assist with outdoor activities. Each day, there are approximately 12-15 members in attendance, all of whom have received a diagnosis of dementia before the age of 65. They are physically healthy (very few have other medical conditions), and are described as having moderate to moderately severe cognitive impairment. More than half the members are men, and there is some cultural diversity in the group. The majority are from middle to upper-middle class backgrounds, although the dementia has led to considerable financial strain for some families. Most members are living at home with their spouse (and sometimes with other family members), but there are a few who

live alone at home with the support of a care partner, or in one case, in a residential care facility. Family members rarely attend the group. Given that these are younger people with dementia, most spouses are employed and use the time to work in support of their family. Members have typically stayed with the club for a period of one to two years, only leaving when they have become too unwell to live at home.

Paul's Club does not adhere to a tightly scripted schedule, although there is a more or less typical pattern to their days. Members gather each morning in a modern downtown hotel that provides their meeting space, and the day begins with coffee and sweets and casual conversation around a table. The group then retires to a seating area where they read newspapers and talk about current events. For an hour or so before lunch there is usually some kind of group activity such as yoga, dance, or more vigorous aerobic and flexibility exercises. The group eats lunch at a lively restaurant next door, and on most afternoons they go for an extended leisurely walk through their neighbourhood, along city streets and waterfront parkland, ending always at the "gelato place" for ice cream. After ice cream, they return to the hotel and prepare to go home. It is these afternoon walks that are the focus of attention in this article.

RESEARCH METHODS

We are reporting here on a subset of data derived from a two-year ethnographic study: *Promoting social citizenship for people with dementia through community based programming*. The larger investigation sought to explore the benefits of community groups for people living with dementia and had two key objectives: 1) to explore how community-based programming

can promote social citizenship for people with dementia; and 2) to evaluate qualitative methods for including people with dementia in the research process. Our focus here is on the first objective, and specifically our analysis from the first phase of the study that was conducted at Paul's Club, where fieldwork took place from October 2014-November 2015.

The primary method of data generation was participant observation (PO), with over 400 hours of PO being conducted over 58 sessions. Kelson was the primary researcher in the field. While everyone was fully informed as to the purpose of the research, her day-to-day role was a participatory one where she was known primarily as a "friend of Paul's Club". The focus of the PO was on members' actions and interactions within the physical and social environment, as well as the verbal and nonverbal exchanges within the group. Jottings were written during each session (often using the text function on a smartphone) to capture details of the activities being observed and especially to document verbatim comments from the members. These jottings were developed into more detailed ethnographic, reflexive field notes immediately afterwards.

Because walking was such a prominent activity for Paul's Club, many PO sessions took place while out walking with the group. Walking alongside participants during PO allowed for spontaneous conversations to occur in an unstructured form, a *go-along* interview (Carpiano, 2009). Members live with varying degrees of aphasia, which made it difficult to engage individuals in a traditional interview that relies primarily on verbal communication. Instead, while outdoors, researchers and members engaged in wide-ranging, spontaneous conversations that were prompted by the physical and social environments encountered while walking. In addition to field notes, conversations were captured in short narratives we refer to as *walking vignettes*. Building on Spalding and Phillips' (2007) discussion of the use of vignettes

in qualitative inquiry and methods developed in Kelson's (2013) critical ethnography of long term care, our *walking vignettes* are composed of researchers' descriptions of, and reflections on, members' bodily engagement with the physical and social environment, relational aspects of the encounter, and recollected excerpts of conversation, for example, a member's reflection on the weather, how they felt at the time, or his or her opinion of the experience.

To further facilitate the involvement of persons with dementia in this research, we invited members and leaders to participate in an hour-long *focus group*. Photographs taken by the leaders while out walking were used as prompts to foster conversation and reflection on club activities. As a visual research method, photo-elicitation is valued as a technique capable of addressing power imbalances found in the conventional research-based respondent-interviewer relationship (Harrison, 2002). Moreover, Harper (2002) maintains that images "evoke deeper elements of human consciousness than do words," suggesting that photo-elicitation has the capacity to not only generate *more* information within interviews, but that this use of photography "evokes a *different* [emphasis added] kind of information" (p. 13) within interviews. In order to elicit these kinds of reflections on members' experiences, we organized a slide show where club members were encouraged to comment on the photographs, which included images of members, group activities, and the places frequented by the group on their afternoon walks. We did this on two different days in the early summer of 2015 to ensure that everyone had the opportunity to participate (n=9; n=11). Both focus groups were audio-recorded and transcribed verbatim, and field notes were taken to describe details missed by the recordings.

Data have been analysed interpretively using the general inductive approach described

by Thomas for “deriving findings in the context of focused questions” (Thomas, 2006, p.237) – in this case, how aspects of social citizenship were constructed and revealed through the group’s practice of walking in the city. Most of the data for this analysis has come from the field notes (FN) and walking vignettes (WV). In addition, we have drawn from the focus groups (FG) described above, a two hour in-depth interview with a family member (FM), as well as document analysis of existing materials that were shared with the team. This included: the group’s website and a promotional flyer; a “guidelines for volunteers” document that was developed by the leaders; results from an anonymous satisfaction survey that was completed by 30 family care partners in the summer of 2014; and a report describing the program that was prepared by the leaders in the spring of 2015 as part of their effort to obtain funding.

Approval for this study was obtained through the University of British Columbia’s Behavioural Research Ethics Board in 2014. Those who were interviewed (either through go-along, focus group, or in-depth interviews as described above) provided informed consent, either directly or in the case of some members, through a proxy. A process consent method (Dewing, 2007) was followed when participants were interviewed more than once, or when they had forgotten the details of the research. This allowed us to revisit and reestablish their agreement to participate at each encounter.

FINDINGS

When we first started this research, one of the leaders told us that in their first year of operation, there had been only three days when the group had not gone out for a walk in the neighbourhood. Rain or shine, she explained, they were out for an hour or two each day walking the downtown streets and the paths along the waterfront park. Through the course of

our subsequent fieldwork, we did note occasions when poor weather kept the group inside, but for the most part these afternoon excursions remain a regular part of the routine, and through analysis of the vignettes, field notes, documents and interview transcripts, we have come to an understanding of how for this group, walking is an act of social citizenship. In what follows, we explore how the members, leaders, and friends of Paul's Club, by walking together through the neighbourhood, are actively constructing social citizenship through: *Keeping the focus off dementia*; *Creating a place of belonging*; and *Claiming a place in the community*. In the findings below, examples from the data (either in italics or in quotes) have come from field notes, unless otherwise indicated.

Keeping the focus off dementia

While the website identifies Paul's Club as a group for people with dementia, from the beginning the leaders have taken it as an imperative that the club provide an explicitly "non-medicalized atmosphere" with an emphasis on "normal everyday activities". Walking is not framed as a program, but rather as the enjoyable pastime of a group of friends. With everyone able to take part, it effectively keeps the focus off the dementia.

The leaders view this as an important way by which they strive to create an environment that is "emotionally safe" (website). At one level, this is about taking care to not confront members with experiences that might cause them to feel distressed. The leaders explain for example how valuable it is that everyone has the opportunity to be out in the community where they can engage with restaurant and hotel workers whose role is to make people feel comfortable and welcome. They contrast this to dementia groups that focus on indoor activities with health care workers who would, they feel, bring more attention to

members' impairment and disability, which would be inherently upsetting. The leaders of Paul's Club refuse to position people in this way, being adamant that the dementia not be the focus of attention. Rather, they view their members as "seeking the same things we all do: to have a role, to feel valued and respected, and to have connection with others" (FN 03-02-15).

This effort to keep the focus off dementia is reflected in the volunteer guidelines that provide direction to "change the topic" or "use distraction" if the subject of dementia or memory loss comes up in conversation, and friends and visitors are often reminded by the leaders to not ask open-ended questions of the members to avoid exposing their inability to answer. In practice of course, these guidelines are not always followed. Members have on occasion been overheard talking together about their dementia (although this happens very rarely) and open-ended questions seem to be a natural part of the everyday conversations that happen in the club. The leaders and friends are well aware that the guidelines are often hard to adhere to, although they are helpful to the extent that they serve as a reminder that Paul's Club is a place where "the diagnosis is left at the door" (promotional flyer).

In explaining their approach, the leaders emphasize "we are not a support group". The family survey revealed that this was an aspect of Paul's Club that was generally appreciated. In a subsequent interview, one spouse spoke specifically of how talking about the dementia "wouldn't fix anything". Rather, when trying to locate a group to meet her partner's needs, she was happy to find in Paul's Club "a place that said, 'we're living, we're living, we are here because we are alive, and we're going to have fun, and that's going to be the rest of my life, just to enjoy every minute...". (FM 11-05-15)

This emphasis was evident amongst the members as well. As noted above, they only rarely spoke of dementia and even then, it was usually in a passing comment such as “I hear they are getting very close to getting a cure for Alzheimers” (FN 11-13-14). In these situations, the conversation between members tended to shift quite naturally in some other direction. The subject of dementia and memory loss simply did not seem to be a topic that aroused much interest. More typical, especially on the walks through the neighbourhood, were conversations that showed members having fun, engaging with what was happening in their environment.

As we walked, C. was very talkative, looking about at his surroundings and responding to what he saw. At one point we watched a small passenger boat go by and it precipitated an extended narrative on its use. He explained how "it ferries people back and forth," his arms making a sweeping gesture across the water. He also talked about the nearby condos and the people living there. While it was hard to understand much of what he said, he was clearly enjoying the day, laughing, talking and walking. (WV from FN 05-20-15)

Good humour plays an important role in “*keeping things light*”. It is evident not only in how members are often laughing and joking (as in the above example), but humour also plays a role in how the leaders and friends of Paul’s Club handle the mistakes and misunderstandings that inevitably occur. Where this often reveals itself is in the time spent getting ready to go out for the walk. It is difficult for many of the members who need assistance in getting dressed for the weather, but the group manages this through intricate interactions that normalize these difficulties and maintain a positive mood. For example, applying sunscreen to someone’s face is accompanied by teasing and gentle laughter, while someone struggling with a heavy coat is

approached with a casual “my zipper is always getting stuck too – can I help you with that?” (FN 11-13-14). Keeping the focus on the task at hand while maintaining positive relationships between friends, leaders, and members is paramount, rather than drawing attention to the problems people are encountering.

Similarly, in the volunteer guidelines, the leaders describe the “*subtle vigilance*” that is required to ensure that everyone stays safe while they are out walking. Ever aware of the possibility that someone may become lost, leaders and friends are quietly counting heads, or walking side by side with members, engaging them in friendly conversation or linking arms as they stroll. These are ways they have found to keep the group safely together but without seeming to do so. The focus remains on the walk itself, and their enjoyment of each other’s company.

Creating a place of belonging

There is a big emphasis in Paul’s Club on the importance of participating together. The leaders, members, friends, and families too, are all very clear that it is a primary aim of the club that everyone shares in activity that is meaningful and enjoyable. The fact that so much of this participation is centred around walking points to the significance of physical activity and movement in their daily routine, with several family members noting how important the “exercise” is, especially for those members who they describe as “still in good shape”. The energy of the group is sometimes hard to accommodate in the confines of the group’s indoor spaces. On those days when the weather is simply too miserable to be outside, some members become fidgety, often getting up to head to the door, wanting to go home. They have a need to move, and an exercise class or a game of ping pong or foosball in the hotel gymnasium is not

always enough. Such activities, which are more structured and contained, do not provide the kind of natural freedom to connect with each other that is afforded by walking in the neighbourhood.

When the group goes out each afternoon, it is not as a tight cohort, but rather as a coming and going of walking partners and shifting conversational groups. There is a lot of flux and movement, forwards and sometimes back, to and fro, with people coming together and parting, and then meeting again. This opportunity to walk and move and go along together, seemingly able to choose where to go and with whom is about having the freedom to participate in a way that is responsive to the shifting needs and desires of the group and its members. It positions the importance of this activity as being so much more than simply exercise.

Walking in the neighbourhood every day together as a group promotes a strong sense of emotional connection and social belonging amongst the members, leaders and friends of Paul's Club. The conversations and physical connections between friends happen quite spontaneously with no pressure to conform to a particular routine or pattern.

D. is fun to be around and great company to walk with. As we set out today he came up to check in and ask how I was doing. ... As we walk, he moves up and down, interacting with others who walk at different paces. He walks a lot with W. I even saw him interact with B. today. As he walks, he offers his opinions on the weather, the lovely day, how lucky we are to be out and about. D. now regularly uses my name and is more physically affectionate, laughing and talking as he gives me a quick hug while we walk together.

(WV from FN 03-18-15)

One family member described Paul's Club as "a place of belonging", and several others have referenced the importance of people walking *together* every afternoon, recognizing that the social connections that are formed and nurtured on these walks really matter. Some described how their spouse had previously withdrawn from the social world, and belonging to Paul's Club had the effect of bringing them back in. We saw evidence of this too in the focus groups; it was the pictures of the group members out walking that generated the most comments. With these, people spoke less often about the activities and places in the photographs, and much more about the people. Members said things like: "*Who is that good lookin' guy? That's you buddy!*" or "*There's P. And I. That's a long time ago, and we're still here!*" (group laughter) (FG, 05-07-15)

Claiming a place in the community

By walking in the neighbourhood, people are afforded opportunity to engage with and contribute to their community. When they are out, it is not as single large group who move together en masse. As described earlier, there is a lot of freedom in their movement, as members engage spontaneously with their environment, exploring together. Much of their time is spent on the various walking paths along the waterfront where they encounter their neighbours who live and work in the vicinity. Those neighbours who are walking their dogs are a big attraction. Group members often stop to engage and play with the dogs, tossing balls, giving them treats, and chatting with the owners.

R. lit up when we walked by the dog park today - there was a lot of action on this beautiful fall day. "Look at them all" she said, highly animated. She spent the next 15 minutes or so handing out dog cookies, patting the odd dog, clearly loving it. Later, on

the way back, walking along a city street she said "They...you know..." She paused. "...respond to me." I guessed that she was talking about dogs, so I replied "Because they're smart, they know...". She responded without hesitation. "They are, more than people." (WV from FN 11-18-15)

When we looked at pictures of these activities during the focus groups, these dogs were identified by name, and even members who were not speaking sat up with excitement, smiling and pointing to the photographs. Time spent with the dogs was a way for people to form social and emotional connections outside the group through enacting their role as a friendly neighbour.

In this way, walking in the neighbourhood is not only a leisure activity, but it also positions Paul's Club members as citizens who have something to contribute to their community, whether it is providing a treat for a dog, or as several of the men do, stopping to talk to the babies who are out with their mothers strolling along the walking path. With advanced dementia, people are typically viewed as vulnerable and in need of help, but on these walks they have the freedom to engage with others and even give back when called upon.

When we left the gelato place I walked with T. for a bit; she was still eating her ice cream in a sugar cone and as we walked past the bus terminal there were several people (sitting or standing) asking for change as we walked past. T. was right beside me when a youngish looking disheveled man approached her, asking for money I thought. This was also T.'s interpretation because she handed him what she had, the remaining part of her ice cream cone. The man gratefully received it. She looked at me and I said how nice it was of her and she smiled and we walked on. (WV from FN, 10-07-14)

This vignette shows walking as an inclusive practice that allows group members the opportunity to contribute more fully to the life of the city. In so doing, Paul's Club is bringing the message into the broader community that it is possible to live well with dementia. Being out in the open, encountering and engaging with local businesses, neighbours and people on the street is a subtle yet potentially powerful way of confronting prevailing assumptions about this condition.

They do this not by advertising themselves or loudly advocating for recognition, but rather through their regular presence in the urban landscape, and when needed, through quiet education and awareness raising activities. For example, there are times when the leaders will share with members of the public a small business card with the following text:

Hello.

We are part of a social and recreational day program for people who are living with Early Onset Dementia. Paul's Club is located in downtown Vancouver and caters to the interests and needs people diagnosed before the age of 65.

Thank you for your understanding.

Staff of Paul's Club

The leaders describe how this has been helpful when there is an interaction involving a member that could be easily misunderstood without this information as important background. They have found this to be one way of increasing public awareness without embarrassing anyone. This makes sense in light of the fact that these members who have significant impairment and trouble with verbal communication would have difficulty explaining such a situation. This card offers a call for understanding and acceptance, not sympathy, and notably, no one individual is

singled out as a person with dementia. In fact, given the younger age range in this group, it would often be difficult to tell just who holds the diagnosis; their disability is not really visible.

That said, over the past year, there has been less call to use the card, perhaps because of the group's regular presence in the neighbourhood. They are more often recognized and greeted when they are out (especially by the dog walkers), and members of the community have over time developed more understanding and ability to engage with group members. The restaurant staff have learned how to better communicate with members, for example, by offering choices ("Tea or coffee?") rather than vague open-ended questions ("What about dessert?"). Similarly, the gelato shop, while at first taken aback by the presence of Paul's Club in their small café, has learned how to make the members feel comfortable and welcome each day.

DISCUSSION

This research has demonstrated how through the practice of walking in the neighbourhood, a community-based activity group is constructing important aspects of social citizenship for people with dementia. In seeking to understand this further, it appears these findings offer a real-life example of the argument put forth by Spinney, Aldred & Brown (in press) that citizenship is not a fixed status, but is performed through everyday experiences of movement and mobility. In what follows, we explore this idea further by building on the findings to show how issues of positioning are fundamental to the work of the group: keeping the focus off dementia opens possibilities for participation and community, but at the same time, creates inevitable challenges for Paul's Club in their effort to ensure the safety of their

members.

The group's commitment to walking every afternoon is guided by a philosophy that foregrounds the importance of continued participation in activities they consider to be "normal". Walking in this context is meaningful precisely because it is so commonplace, an "(almost) universal activity" (Pink, 2007, p. 244). Everyone in the neighbourhood walks, and ensuring that people with dementia are out walking too is a way of upholding their position as social citizens. In discussing the distinctly social nature of walking, Ingold & Vergunst (2008) note that "not only do we walk because we are social beings, we are also social beings because we walk" (p. 2). In this vein, we might say that members of Paul's Club not only walk, but *are* walkers, their movement through the neighbourhood serving to enact this shared social identity.

The group's emphasis on "normal" is evident also in the care taken in every interaction to keep the focus off dementia. This may be best understood as a kind of positioning work through which Paul's Club is resisting the power of the dementia label in a constant effort to centre the *person* rather than the disease. It is evident from these interactions that the people of Paul's Club know each other very well. Their concern for the social positioning of the members is shown in a profoundly relational approach that allows each person to be treated with respect and dignity as a unique individual.

In purposefully identifying each individual as a member of a club (and explicitly *not* a client of a formalized day program), Paul's Club is seen to be building a community of people brought together by a strong sense of belonging. This is due in part to the relationships within the group where people come to know and care for each other. But Paul's Club as a place of

belonging also comes from the way that members, as walkers, are themselves contributing to the life of the group through their participation together in this everyday activity. There is not a passive involvement, but an active co-construction of social belonging and community.

Walking every afternoon is a way of extending this into the neighbourhood, where Paul's Club is contributing to the creation of a more inclusive urban space, allowing people with dementia to claim their rightful place in the broader community. When they are filling the tables in a small gelato shop at the end of their walk, they offer no apologies. As a group, there is a complete and fulsome engagement that demands they be socially regarded (Brannelly, 2011), and aims toward creating public spaces that are actively inclusive of people with dementia.

To some degree then, the group might be seen as helping shift the discourse around memory loss by raising awareness that it is possible to live well with dementia, thus building social capital and contributing to the growth of dementia friendly communities (Keady et al., 2012). Through creating opportunity to be involved in activities that anyone would enjoy – not just people with dementia (Menne, Johnson, Whitlatch, & Schwartz, 2012), Paul's Club is effectively standing up to the stigma of this condition (Genoe, 2010).

The group does not take this as their primary aim however. While remaining firm in their commitment to be out in the community, doing so *as* people with dementia creates certain tensions within the group. Where this becomes particularly evident is in relation to issues of safety.

Walking through an urban neighbourhood carries a degree of risk for anyone, but especially so for people with dementia. Crossing busy intersections, avoiding unpredictable

bicycle traffic, and simply staying together are persistent concerns for the leaders and friends who take responsibility for ensuring the group's physical safety. The members embody a particular confidence when they are out, and given the freedom they have on these daily walks it is not unusual for them to make their own way, sometimes taking their leave from the rest of the group. The leaders and friends are ever aware of this possibility and are constantly keeping watch.

The surveillance practices of the group are carefully enacted though, with the intent that they not draw attention or seem out of the ordinary. This comes from the group's concern that they do everything possible to maintain members' social dignity, especially when they are out in public where people with dementia are far more likely to experience such affronts (van Gennip, Pasman, Ooserveld-Vlug & Philipsen, 2014). However, keeping the focus off dementia while still having to acknowledge the group's very real vulnerability and need for protection is where things get difficult. Working as they are in the "grey area of diminished capacity" (Behuniak, 2010), the primary issue the group confronts is "how to achieve a balance between rights and protections" (p. 238) - how and where are they to walk so people can safely enact their right to participate in the life of the community? Focusing on the person *rather than* the dementia may not be the most helpful framing for considering this question, given the inference that the dementia should not matter when clearly it does. Instead, what this research has shown is how Paul's Club is negotiating the complexities of walking in the neighbourhood as a practice of social citizenship that centers the *person with* dementia (Barlett & O'Connor, 2007, p. 114).

Resisting the power of the dementia label is an appealing notion, but in the practical

exigencies of their daily walk, this resistance can never be complete. It exists alongside the group's very real need to acknowledge the dementia in their midst. Centering the *person with dementia* is a difficult balancing act to be sure, but at the same time it represents a potentially important shift in perspective that recognizes members as both vulnerable *and* agentic, and the practices of the group as resting on principles of compassion *and* empowerment (Behuniak, 2010).

CONCLUSIONS

In drawing conclusions, we begin by commenting on how this work brings to light the innovation of a group like Paul's Club. Being situated on the margins of the health and social care system, they have a certain freedom to do what seems most fitting for a group of younger people with dementia who otherwise have very few services available to support them. Explaining how the group's practice of walking through the neighbourhood constructs social citizenship in terms of positioning, participation and community may contribute to further theorizing, but hopefully has practical implications as well. By providing a way of framing and articulating the complexity inherent in this everyday activity, the research may have potential to contribute to the development of community-based initiatives that build on the important work being done in Paul's Club. For example, this evidence could help shape policy and practices aimed toward the creation of dementia-friendly communities, and more specifically, influence the further development of services around the idea of leisure and citizenship, especially for people with young onset dementia.

Of course, there are limitations in what we have presented here. Enacting citizenship through everyday practices of movement and mobility is not entirely unproblematic, and there

are certain points that have not been considered in this analysis. For example, we have not addressed in this paper the fact of the group's privilege, particularly in light of their physical wellness. While there is a broad age range amongst the members of Paul's Club, overall they are more physically robust than more traditional dementia groups. There are usually one or two members who are less mobile (being slow, or having poor balance or diminished step height), but the group is able to accommodate this within the practices described earlier (e.g. walking side-by-side or linking arms). But that said, the analysis presented here should not be taken as an argument that social citizenship requires such mobility. Rather our aim has been to show how this particular group enacts citizenship in this particular way, and the complexities they negotiate in the process. Enacting citizenship would be quite different if the circumstances were otherwise, e.g. if the group was older and more physically frail, or they were in a neighbourhood that was less conducive to walking. With the current research, we have begun to develop an evidence base for understanding how community-based activity can contribute to social citizenship for people with dementia. However, recognizing the importance of structural influences on this process, as we move ahead with the next study site we anticipate taking the analysis in that direction to explore more explicitly issues of age, place, and related sociocultural factors.

Declaration of Conflicting Interests

The authors declare that there are no conflicts of interest.

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