

'Overjoyed that I can go outside': Using walking interviews to learn about the lived experience and meaning of neighbourhood for people living with dementia

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Abstract

This study explores the relationships between people living with dementia and their neighbourhood as they venture out from home on a regular and often routine basis. Here, we report findings from the Swedish fieldsite of an international 5-year project: Neighbourhoods: our people, our places. The aims of this study were to investigate the lived experience of the neighbourhood for people with dementia and through this to better understand the meaning that neighbourhood held for the participants. In this study, we focus on the walking interviews which were conducted with 14 community-dwelling people with dementia (11 men and 3 women) and were analysed using an interpretative phenomenological method. Four themes were revealed from these interviews: life narratives embedded within neighbourhood; the support of selfhood and wellbeing through movement; the neighbourhood as an immediate social context; and restorative connections to nature. These themes were distilled into the ‘essence’ of what neighbourhood meant for the people we interviewed: *A walkable area of subjective significance and social opportunity in which to move freely and feel rejuvenated.* We have found that the neighbourhood for community-dwelling people with dementia holds a sense of attachment and offers the potential for freedom of movement. Our research indicates that a dementia diagnosis doesn’t necessarily reduce this freedom of movement. The implications for practice and policy are considered: future research should explore and pay closer attention to the diverse living conditions of people living with dementia, and not least the particular challenges faced by people living alone with dementia.

Keywords: Neighbourhood, dementia, community –dwelling, lived experiences, interpretative phenomenology, walking interviews

Introduction

A desire on the part of older people to ‘age in place’ has been widely reported in gerontological research and increasingly supported through policy innovations such as the promotion of ‘lifetime homes’ (Hanson, 2001) and the design of age-inclusive environments (Fitzgerald & Caro, 2014). As a result, a growing proportion of older people are being supported at home rather than admitted to long-stay care. It has been argued that ageing in place is important because home is a locus for a sense of belonging which supports wellbeing in later life (Board & McCormack, 2018; Wiles, Leibing, Guberman, Reeve, & Allen, 2011; Vasunilashorn, Steinman, Liebig, & Pynoos, 2012).

A similar picture is seen for people with dementia, although supporting research is sparse when it comes to understanding the distinctive challenges of ageing in place with a progressive condition. Existing research has shown that people with dementia are at risk of becoming isolated in their homes (Aminzadeh, Dalziel, Molnar, & Garcia, 2010; World Health Organization, 2012). In Sweden, a great majority of people with dementia (about 72 percent) are living at home and around half of these are in single households (Odzakovic, Hydén, Festin, & Kullberg, 2018). Indeed, the number of single-householders living with a dementia diagnosis in Sweden is rapidly expanding (Wattmo, Londos, & Minthon, 2014). Communities need to be aware of this growing demographic, while local and national governments should ensure that people with dementia living in diverse social and material-contexts are equally well supported to remain involved and active in their neighbourhood (Soilemezi, Drahota, Crossland, Stores, & Costall, 2017). These recent changes imply the need for research that helps us to understand what enables people with dementia both to remain at home *and* stay engaged with their neighbourhoods. The study

reported here therefore aimed to address current gaps in research by examining day-to-day neighbourhood living for community-dwelling people with dementia.

Neighbourhoods are often understood and defined according to geographic boundaries or as administrative zones created for the purposes of local governance (Galster, 2001). However, the concept of *neighbourhood* has many more social and subjective connotations and interpretations, and could be defined from a more experiential perspective as a place where people structure their outdoor environment (Bernard, Charafeddine, Frohlich, Daniel, Kestens, & Potvin, 2007). Some commentators have argued that the neighbourhood starts indoors, with the view through a window and subsequently continues out into the local environment (Tang & Brown, 2006), while others have suggested more prescriptively that it can be understood to extend to a walkable radius of 5-10 minutes' distance from home (Kearns & Parkinson, 2001; Galster, 2001). Previous research has shown that accessible neighbourhoods have great significance for independence, access to green spaces, quality of life and mobility in later life (Galster, 2001; Michael, Green, & Farquhar, 2006; Möttus, Gale, Starr, & Deary, 2012). Blackman (2006) has also drawn attention to the material and spatial dimension of neighbourhoods, arguing that they be understood as embedded in built environments, with resources such as primary care health centres and other services located in ways that mediate people's access to support. For Blackman, the neighbourhood is comprised of mobility patterns, as people move from one 'node' to another from their home, creating a "*walkable zone of experience*" (Blackman, 2006, p. 107). These 'walkable zones' include temporal, experiential and spatial factors that connect into a multi-layered people-environment system (Blackman, 2006). Beyond these factors, the neighbourhood is a central social space to preclude loneliness for older people (Phillips, Siu, Yeh, & Cheng, 2005). In this respect, the neighbourhood is formed of a dynamic bond between social and

physical factors (Macintyre & Ellaway, 2003). One approach to better understanding this dynamic connection is through bodily engagement with the neighbourhood by walking in and through it (Eronen, Bonsdorff, Rantakokko, & Rantanen, 2014).

Existing research into the relationship of people with dementia and the environments they inhabit has mainly focused on questions of ‘wandering’ and the risk of getting lost outdoors (Bantry White, & Montgomery 2016; Lai, & Arthur, 2003). More recently, there has been a concern with questions of accessibility to enable people living with dementia to independently navigate their way through urban environments (Blackman, Van Schaik, & Martyr, 2007; Burton & Mitchell, 2006). However, there is little research on how people with dementia experience public spaces and everyday life in the neighbourhood (Keady, et al. 2012; Keady, 2014). One message from a number of studies has been that following diagnosis, people experience a “shrinking world” and as the condition progresses so access to the neighbourhood as both a physical and social space decreases (Duggan, Blackman, Martyr, & Van Schaik, 2008; McShane, Gedling, Keene, Fairburn, Jacoby, & Hope, 1998). Caregivers have also been found to experience something of a shrinking world, as social relationships and activities become limited due to increasing caring responsibilities (Silverman, 2017; Ward et al., 2012). However, it has been argued that for informal caregivers, the experience of a shrinking world can be challenged by walks in the neighbourhood; the act of walking itself supports social relationships and connection with the neighbourhood (Silverman, 2017). Regarding access to the neighbourhood, studies have shown that people with dementia can often adapt to and manage different types of situation in public spaces such as grocery shopping and crossing busy road intersections (Brorsson, Ohman, Lundberg, Cutchin, & Nygard, 2018; Brorsson, Ohman, Lundberg, & Nygard, 2011). Furthermore, early findings from the Neighbourhoods: our people, our places project (Ward et

al., 2017) point to the importance of understanding neighbourhood as ‘lived place’ that is rooted in the day-to-day experience of people with dementia, rather than as a fixed or static physical entity. The research has begun to reveal how people’s identities are embedded in the neighbourhood. Hence, people with dementia and informal caregivers value the neighbourhood as a place that supports a sense of belonging, through social connections (Silverman, 2017; Ward et al., 2017).

The rationale for this study is therefore based on the importance of finding out how community-dwelling people with dementia use and interact with their neighbourhood, in order to uncover new knowledge about everyday life with dementia. Such knowledge and understanding is also crucial to the rapidly evolving field of dementia care practice as it shifts from institutional settings to a growing emphasis on community-based support, increasingly organised under the banner of ‘dementia-friendly communities’ (Alzheimer’s Disease International, 2016).

Methods

The context of the study

This study reports on research undertaken as part of the “ Neighbourhoods: our people, our places project (N: OPOP). This 5-year, qualitatively-led project, funded jointly by the ESRC and NIHR is itself part of a wider programme on Neighbourhoods and Dementia (see Keady, 2014; neighbourhoodsanddementia.org for further details). N: OPOP project extends over three field sites: Fourth Valley (Scotland); Great Manchester (England); and the county of Östergötland (Sweden) and here, we present and discuss findings from the Swedish fieldsite, but with reference to the wider project.

Aims and research questions

The over-arching aim for the study was to investigate the lived experience of the neighbourhood for people with dementia and through this to better understand the meanings that neighbourhood held for the participants. At the outset we formulated two research questions to guide the research:

- How, if at all, can a neighbourhood support people to remain socially and physically active following a diagnosis of dementia? and,
- What meanings do people with dementia attach to their experience of neighbourhood living?

Research Methodology

The study as a whole was framed according to a social constructivist paradigm (Creswell, 2013). Given our desire to better understand the meaning that neighbourhoods held, an interpretative phenomenological method (Moustakas, 1994) was chosen as a framework for data analysis. A phenomenological approach fitted the opportunity to elucidate the neighbourhood phenomena through walking and talking within it (Morris, 2004). The importance of walking can be understood from a phenomenological perspective; it enables an embodied connection with the outdoor world (Morris, 2004) and movement through both the landscape and through time (Solnit, 2001). The phenomenological approach derived from Merleau-Ponty centres around the notion of the ‘mind-body-world system’, and this connection cannot be explained outside of the situated, lived experiences of everyday life, which are both embodied and intersubjective

(Merleau-Ponty, 1962).

Earlier research has also demonstrated the value of using walking interviews with participants with dementia, although this has often been in the context of group-based guided walks (Phinney, Kelson, Baumbusch, O'Connor, & Purves, 2016; Kelson, Phinney, & Lowry, 2017). Our choice of walking interview was shaped by the wider participatory ethos of the study. As we have discussed elsewhere (Kullberg & Odzakovic, 2018), walking interviews are particularly supportive of the involvement of people with dementia in the research process (Scottish Dementia Working Group, 2014). Taking the approach of walking and talking generated data about life that takes place in the neighbourhood for the participants who were prompted by their physical presence in the chosen setting to share their lived experiences. The participants were asked to lead the walk (Kusenbach, 2012), to decide which route we followed and the pace of the walk and in this respect exercised greater control over the interview process than might have been the case for more sedentary data-gathering.

Ethical issues

The study was approved by the Regional Ethical Review Board in Linköping (record no. 2013/200-31). The participants gave informed consent in both oral and written form before the walk commenced and we followed a process consent approach (Dewing, 2007) ensuring at regular intervals that individuals were reminded of their participation in the study and aware of their right to withdraw or temporarily halt the interview. During the walking interviews themselves, the participants decided whether to reveal the purpose of the walk to their neighbours and anyone else they encountered along the way. The researchers had to be sure that the

participants could manage to walk and throughout we monitored for any signs of tiredness (Kullberg & Odzakovic, 2018). If any of the participants were unable to walk, then the researcher could suggest an interview at home instead, or possibly returning another day. We have used pseudonyms throughout the reporting of data to maintain confidentiality (World Medical Association, 2016).

Walking interviews

There have been a number of studies using walking interviews involving older people (Alidoust, Bosman, & Holden, 2017; Brittain, Degnen, Gibson, Dickinson, & Robinson, 2017; Büscher & Urry, 2009) and with carers to people with dementia (Silverman, 2017, Ward et al., 2012), however, so far very few studies have been conducted using mobile methods, such as walking interviews with people with dementia (Kullberg & Odzakovic, 2018). Walking interviews have been shown to enable more spontaneous conversation with participants, while generating focused and specific data about the place and social life of the neighbourhood (Carpiano, 2009). Some commentators have argued that walking interviews are more closely aligned to ‘naturally-occurring’ interactions and therefore more true-to-life than other methods (Hall, 2009). Walking also necessarily involves embodied patterns of movement, offering opportunities to learn from the non-verbal aspects of people’s engagement with their local environment (Büscher & Urry, 2009; Clark & Emmel, 2010). For those individuals who are able to do so, walking as an act, *per se*, could support a sense of freedom of movement (Solnit, 2001), empowering people to take control of their movements and choice of direction and through this generating a degree of well-being (Evans & Jones, 2011). Walking in the immediate environment of the neighbourhood can

also create meaningful interactions between space, time and experience through an individual's knowledge of place (Hein, Evans, & Jones, 2008).

Participant recruitment and setting

After ethical approval, the authors (EO, AK) contacted and visited memory clinics, primary health care and day-care centres in the county of Östergötland asking healthcare staff to contact them with details of any possible participants. Inclusion criteria used for selection were: a dementia diagnosis, community-dwelling, and capacity to give informed consent.

Potential participants were contacted first by letter and then a follow-up telephone call.

Involvement in the research began with a rapport-building 'sit-down' interview, which included an introduction to the study. Having established contact, the researchers then arranged a second visit to conduct the walking interview after securing informed consent. In total, 14 community-dwelling people with dementia participated in walking interviews. Table 1 below shows that the participants ranged in age from 62 to 87 years; 11 were men and 3 were women, and 6 participants were married and living with their spouse. All participants were diagnosed with a dementia, however the length of time they had lived with the condition varied. At the time of interview, all the participants were able to manage their day-to day activities independently or with assistance from caregivers and/or municipal home care.

Insert Table 1 here.

Data collection

The authors (EO, AK) conducted the interviews, which were audio-recorded. The time and place for walking interviews were chosen by the participants. The participants often took the role of ‘tour guide’ (Ward et al., 2012), deciding the direction and duration of the walk and two (of the 14) participants chose to have their care-partner accompany them. The walking interviews were done in all seasons but always during daylight hours. Some of the participants had an aid e.g. walker to maintain balance during the walk (Table 1), and none chose to withdraw during the interview.

The interviews were conducted more as a ‘walk and talk’ than a formal interview; using conversation to create a relaxed and trusting atmosphere. We explored questions of the environment, local services, people and buildings in the neighbourhood using open questions such as: “Can you describe a typical day in the neighbourhood?” and followed by probing questions (Lincoln & Guba, 1985) such as “Tell me about that experience?” to encourage the participants to talk about their lived experience of the neighbourhood. After the walking interviews, field notes were made that were used to inform the analysis (Moustakas, 1994). The walks lasted from 25 to 97 minutes and were transcribed verbatim by a certified transcriptionist and the authors (EO, AK).

Data analysis

The coding and analysis of the walking interviews followed four main steps according to Moustakas’ modified version of the Stevick-Colaizzi-Keen method (Moustakas, 1994), and were compatible with an interpretative approach in accordance with the aims and research questions.

As a first step to the analysis, the transcripts were read several times to gain an overall understanding. When a full description was completed, the authors applied their own knowledge (field notes) and experiences of the phenomena (meaning of the neighbourhood) to the description (pre-understandings). In the second step, all transcripts were re-read to find statements of relevance to the aims of the study. Each statement was divided into units of meaning and uploaded to a spreadsheet to gain an overview of the developing themes. In this step, mind maps were designed based upon what the participants had drawn our attention to during the walks. The mind maps were a tool for establishing a description of the phenomena and in order to create them, the methodological terms of ‘noema’ and ‘noesis’ were employed. The noesis and noema provide a link towards our perception of the world. Noesis can be understood as our thought towards the object, while the corresponding noema, refers to the object of our perception itself, what we ascribe to “the appearance *of* something in our world” (Moustakas, 1994). We can demonstrate these two concepts through an example from our analysis when the participants were walking in green spaces and they draw directly their attention (noesis) towards the physical forms *of* flowers (noema) in the neighbourhood. This working procedure lead on to find the essential themes. For further information about the examples from the analysis see Figure 1 from one of our participants. In the third step, a formative description with quotes from the transcripts was created based on the mind maps. In this fourth step, an overall description of all mind maps was establish and the essences of the phenomena were found. was helpful in order

Insert Figure 1 here.

Findings

From the analysis of the walking interviews, four themes were identified and will be presented below:

- Life narratives embedded within the neighbourhood
- The support of selfhood and wellbeing through movement
- The neighbourhood as an immediate social context
- Restorative connections to nature

The four themes were distilled into the ‘essence’ of the lived experiences and meaning of neighbourhood: *A walkable area of subjective significance and social opportunity in which to move freely and feel rejuvenated.*

Life narratives embedded within the neighbourhood

During the walks, the neighbourhood environment prompted participants to share a range of experiences from across their lives that were linked to place, such as events from childhood, working- and family life, as well as looking ahead to future plans. The terrain of the neighbourhood was intimately well-known for many, as indicated by the way in which the neighbourhood mediated so much of their personal histories. Many participants gravitated toward places in their neighbourhood of special meaning to them.

“I’ve lived here my whole life, so I know ... And I used to run this football ground for the kids, once upon a time. I would come here and take care of the football ground, cut the lawn, for over thirty years.” (David, 75-year-old man)

The walking interviews helped the participants to recall life narratives that were embedded in their neighbourhood. Fanny, Simon and Lennart all shared life events from their childhood neighbourhood, illustrating how places in the here and now can transport people to imagined and remembered places of the past. Happening across a particular building, or even a local cemetery could also prompt memories even if those recollections were not tied specifically to the places we were visiting. For instance, Fanny called to mind the neighbourhood of her childhood, a place that was tied up with memories of her parents.

“There is nothing left in [childhood neighbourhood] now or before, we had three groceries and meat shops and café. My parents had a café in [childhood neighbourhood]”. (Fanny, 87 years-old- women)

Fanny’s recollection indicates how neighbourhoods can change around people and gradually become a different place to that of their memories from youth. A dog was central in Lennart’s life, which he walked every day, a routine that he had been keen to continue following despite the onset of memory problems. Lennart had been a company manager, and as we walked by his local cemetery, he reflected on the colleagues who had been laid to rest there:

“We have the church there, you see up there to the clock yard, where he lives, he (former working colleague) has an overview of the neighbourhood. I know most people who are in the cemetery who have lived... and worked with me.” (Lennart, 82-years-old)

The importance of remembered and imagined places became clear as we walked together, these places were all part of the ‘lived neighbourhood’ for our participants, that supported their

identity. Some of the participants adjusted to a new neighbourhood, despite only having lived there for a few years of their lives. One of the participants, Yngve not only shared memories of his neighbourhood from the past, but was also able to plot the changes taking place in the present, for instance where buildings had been renovated for new purposes.

“The house there was a mechanical factory, where that car is standing. There used to be three companies, but now there’s only one company left. There are new buildings all over there...”

(Yngve, 74-years-old-man)

During the walks, the landscape provided opportunities for participants to present biographical experiences from the past but also to share hopes and dreams for their life ahead. For some participants, their futures were signalled during the walks through mention of their plans for moving to a new dwelling or neighbourhood in the event that their situation were to change or deteriorate. Others discussed future plans for holidays or ideas for developing their current neighbourhood in the future. Hence, people with dementia expressed and moved between different temporal dimensions as they made their way through the neighbourhood; our conversations flowed between past, present and future in ways that were shaped by the landscape and the objects and features within it.

Support of selfhood and wellbeing through movement

Walking in the neighbourhood was essential to everyday life for the participants, but it was also vital to their sense of self as expressed by Fanny: *“I am so happy as long as I can walk on my own two feet and shop by myself”*. During the walks, the participants emphasised the value they

placed upon having freedom of movement. A walking aid or even the company of a dog served to support and improve bodily movement, and to sustain a relationship with the neighbourhood.

Lennart noted that walks with his dog encouraged him to go out on a regular basis *“It varies a bit, long walks in the morning and short in the evening. Yes, it's at least a one-hour walk, for the most part. We walk 5 km there and 5 km home”*.

This passion for walking suggested perhaps a local culture of staying active, and recognition that regular activity had implications for health. Some of the participants suggested that walking was good for the brain and for slowing the progression of dementia. Ingvar, who was 62 years old, had lived alone in the same flat for the last 20 years, in a small neighbourhood where he had grown up. Ingvar had a son who helped him with his finances and ran a few errands for him after Ingvar had declined help from home care services. From his window, he could see down to his former school, and he recalled how his mother had encouraged him to write during his youth. Subsequently, Ingvar had become an author and enjoyed writing and reading poems, sometimes for an audience and had continued writing following his diagnosis. At the time of interview, he had been living with Alzheimer`s and vascular dementia for two years and had further health problems that required him to walk with the use of a walker. Ingvar drew particular attention to the importance of walking while living with a diagnosis of dementia, while also underlining his awareness of the stigma surrounding dementia (Figure 1):

“I go out almost every day because my doctor has said that being around people, having same routines every day and walking is good for my brain... I take control over myself then, and it has got much better. But when you`ve got Alzheimer`s, everyone thinks that one is just destroyed, which is completely wrong.” (Ingvar, 62-years-old man)

The presence of nearby green spaces and pedestrian walkways, away from traffic appeared to be particularly attractive destinations, encouraging people to get out of the home for a walk.

Movement through walking was seen by many of the participants as beneficial to mind and body, lowering stress levels and enhancing well-being. We learned about the importance of re-treading familiar ground, following routines and keeping up day-to-day patterns of activity. The participants emphasised the importance of walking not only as central to their well-being and their efforts to manage life with dementia, but also as a means to maintain a positive self-image and to actively perform different aspects of their identities.

The neighbourhood as an immediate social context

Social relationships located in the neighbourhood were important for the participants but were carefully managed according to local cultures and practices relating to social interaction.

Interestingly, in contrast to the close neighbourly relations outlined by many participants from the UK fieldsites (Ward., 2017), we found that the Swedish participants tended toward a more cautious relationship with the people who lived immediately around them. For instance, Cecilia revealed that she would greet her neighbours when she saw them but that she didn't want to socialise with them. Some other participants noticed the new generation of young families moving in to the neighbourhood, with whom they had less in common but highlighted the importance of being part of an intergenerational neighbourhood.

Anna shared another view of neighbourhood as a context for potentially finding new social contacts. Anna was 78 years old and was diagnosed with Alzheimer's disease six years ago. She

was living alone in a flat on the third floor with an elevator and received no support from home care services. Anna told us that she had to move to a new flat so that she could continue to go out by herself with her walker. It was essential to Anna to get out and have accessible walking trails close to home. She tried actively to establish new social contacts through activities such as bingo every week. However, in the summer months there were fewer social activities on offer and during this time she would sit on a bench located in the centre of the neighbourhood near a road, in order to watch the cars go by, but also in the hope of the opportunity to chat with someone. This bench proved essential for Anna during the summer period:

“In summer, this long summer, then it's almost a small meeting point for those of us who are retired. It's our pleasure, we're counting cars here. I can sit for a while and sometimes there is nobody to talk with, sometimes there is someone that I can talk with”. (Anna, 78 years-old-women)

Many of the participants sought out potential social meeting places in their neighbourhood, places they would visit regularly to find other people to meet and chat with. Anna described the loneliness she felt every day and the challenge to finding new friends after moving into a new neighbourhood in later life. It had proven difficult because many older residents already had well-established friendships. Some participants shared a perception of being socially excluded, but not always as a result of having dementia, Cecilia interpreted her situation as the result of being on her own: *“I have some friends but the worst is to be lonely, and old friends disappear. I would never have dreamt it - but you know they have the perception that you should be part of a couple. So then you do not fit in their social circle when you are alone”.* We might also understand such experiences as examples of ageism, overlaid with the stigma surrounding dementia.

It was not only Cecilia whose social networks had depleted over time, a number of participants noted they had fewer people in their lives and more fleeting and time-limited encounters in their neighbourhood, but far fewer opportunities for more prolonged sociability. By contrast, those participants who had lived in the same neighbourhood for many years often had greater levels of social contact and were sometimes described as “native” citizens by their new neighbours, a label of which they were proud. For Urban and his wife, their attachment to their neighbourhood had been reinforced by their general practitioner (GP) who had advised them to stay put and not consider moving:

“The neighbours call us ‘native inhabitants’. We have lived here almost 50 years. But we will not move from here. We’ve been advised not to do so from my doctor because I have dementia . Things could get difficult then.” (Urban, 81-years-old-man)

“Half the city says hello when we go out, you cannot get around the corner without meeting old pupils, or patients. Therefore, we live in an area with great social connections” (George, 79-years-old- man)

A sense of attachment could also result from a shared local culture and identity that characterised people’s outlook and sense of humour:

“We, citizens of this town, we are .. yes .. how can I put it - we are our own people. The unique thing about this town is the people living here. We have our own jokes "Tomorrow we'll have

rain” we'll both point out and respond at the same time "tomorrow it will be rain, will it?"

(Laughs)” (Jerker, 68-years-old-man)

Opportunities to interact with other people in the neighbourhood were clearly important for the participants we spoke to and were often actively sought out. Some people established new social activities which provided the chance to spend time in the company of others. The participants living in couples usually cited their partner as the primary source of social contact, while those living alone reported relying more upon municipal home care services. For some, these home care visits could be their only social contact for the day and provided the support they needed to go for a walk in the neighbourhood. This picture of different situations between those living alone compared to those with a co-habiting caregiver shows the need for more knowledge and understanding of the social relationships for single householders. The neighbourhood is essential in providing the most immediate and easily accessible social context for many people with dementia - to meet, chat or wave to someone in the places and spaces that surround their home. In this context, walking was a means to stay connected as well as active. And, for all the participants the neighbourhood held a promise of forging new social contacts as well as holding onto existing ones.

Restorative connections to nature

During the walking interviews, particular attention was drawn to scenic and open spaces in the neighbourhood by the participants as they adopted their role of tour guide. These places were often green and more natural settings such as public gardens and woodland. The participants made it clear during interview that these places had a positive impact on them, enhancing their

sense of wellbeing. Maintaining a connection to nature was felt to be restorative, and the participants shared their excitement at spotting animals or the pleasure of looking at flowers during their day-to-day movement through the neighbourhood. Indeed, Anders and Simon made it clear that green and natural spaces were by far their preferred type of environment. During interview Anders and Simon communicated their passion for nature and encountering the local wildlife.

“It’s easy for me to go out into nature, I love it and I will always do it. I’m happy and overjoyed that I can go and stay outside. When I go out I can find red clover and everything in nature. (Anders, 80-years-old man)

“I’m drawn to the forest and to nature, to experience all the noise and to hear the wind, but above all, to meet a bird or a little rabbit“ (Simon, 79- years-old man)

In addition to being drawn to the flora and fauna, many participants mentioned their enjoyment of the changing landscape as one season shifted to another and in different weather conditions. Two of the participants Per, and Nils noted the sunshine and Spring flowers.

“It is very nice, when the sun shines and to see the colours on the oaks. Look how different the oak is because it still has more leaves left than the others.” (Per, 77- years-old man)

“Early in the Spring... we usually go here (referring to a place in the neighbourhood), more than in winter. When the sun shines then we usually stand here. There’s usually a lot of Hollyhocks every Spring” (Nils, 73- years-old man)

The changing seasons symbolised hope and the chance to rejuvenate for some of the participants as they began to notice the early signs of Spring after a long winter. Time spent outdoors in nature was combined with restorative practices such as walking that helped participants to manage life with dementia. Hence, green and natural spaces in the neighbourhood were an essential part of the lives of the people we interviewed, and many actively sought out places of natural beauty and the more calming and less busy parts of their neighbourhood.

Essence: A walkable area of subjective significance and social opportunity in which to move freely and feel rejuvenated

In drawing together the different themes it is clear that the neighbourhood offered a series of settings and contexts that often held significance and meaning for our participants based upon their biographical links to local destinations. People sought out green and open spaces that were free of traffic and crowds and which allowed them to move freely without facing the stress or challenge of busy roads or congested pavements. The neighbourhood was reproduced for them through their routine movements within it, often it involved habitual spaces where repeated visits over time helped to create a sense of attachment and belonging. In this way, even very mundane journeys to the shops or to walk the dog, created continuity and a sense of self in both time and place. Walking was identity-affirming and this emerged from an embodied connection (bodily knowledge in the legs) and multi-sensory engagement to place rather than a more cognitively-driven sense of attachment, and it was clear to us how the significance of this embodied connection would likely increase as the dementia progressed. The participants used their movement through the neighbourhood as a way of sharing the meanings that the world held for

them, in the past, the present and in looking ahead to a future living with dementia. Thus, through their bodies, the participants attended to the neighbourhood according to perceptions and structures which had built up over time. While some had aged in place, others needed to establish new social connections and even here the ability to freely move about the neighbourhood was paramount to maximising social opportunities and forging new relationships. Ultimately, walking through the neighbourhood enabled freedom of movement, something that reinforced a sense of autonomy, allowing people to feel in control of their lives and at times, to escape the pressures or isolation associated with their homelife.

Discussion

Merleau-Ponty (1962) argued that: “*The lived body (Leib) is also something physical that calls for a pre-existing place-world: it’s aware acutely when it’s walking*”. By walking (and talking) we sought to encourage people living with dementia to share their lived experiences of their neighbourhood and tap into the awareness that comes from embodied movement through their ‘place-world’. Earlier studies have suggested that people with dementia experience a shrinking world following diagnosis, often as result of the progression of dementia (Duggan et al., 2008; McShane et al., 1998), however, our findings differ from this conclusion. Instead, we have taken a perspective based on a phenomenological approach (Moustakas, 1994; Morris, 2004) where we have explored the meaning of neighbourhood to be a “*walkable area of subjective significance and social opportunity in which to move freely and feel rejuvenated*”. From this essence of the data we argue that people with dementia actively challenge the prospect of a shrinking world by exercising a freedom of movement; gravitating dimensions (noema and noesis) of their particular attention within and towards places that supported their sense of self and wellbeing; and by

seeking out opportunities for sociability. Physical movement helped people with dementia to express the meanings that the neighbourhood held for them as their bodies interacted with the environment. Such learning is of value as it provides a counter-narrative to earlier studies that have tended to pathologise the movement of people with dementia, especially those in the latter stages of the condition by labelling it as ‘wandering’ (Bantry White, & Montgomery, 2016; Lai, & Arthur, 2003). Wandering has been examined mainly in places such as care facilities where the environment is often unfamiliar and outdoor access is limited (Brittain et al., 2017). In this study, the participants emphasised the significance of having access to a walkable area outdoors within proximity to their home, where they could enjoy freedom of movement. Referring to the tendency to label walking as wandering in care facilities, our study has shown clearly that walking is a lifelong activity that creates a connection to an inclusive neighbourhood and the rich sources of sensory stimulation that it offers. As such, care providers need to understand patterns of movement in a biographical context. Further, this study challenges the perception of people with dementia as passive, or as struggling to remain oriented in time and place (Caddell & Clare, 2011). The participants saw possibilities instead of difficulties in the meaning of living with dementia and in this way challenged broader social assumptions and stigma associated with the condition. We extend previous research and suggest that people with dementia living in their own home, can adjust to new environments and move reflexively between temporal dimensions in the neighbourhood. One explanation for this finding could be that day-to-day experiences of the neighbourhood, as well as memories of it, are absorbed at a bodily level, built up through patterns of walking that ultimately shape a person’s sense of self, and wellbeing as well as their connection to place. Participants in this study were looking ahead, thinking and reflecting on plans for the future, and we argue that it’s important to acknowledge that a person living with dementia still has a future and often wishes to anticipate and prepare for it and should be

supported to do so.

Beyond the importance of the walkable area where the participants could move freely, their attention was also focused upon being part of a wider social context. It would often require creative strategies to challenge the potential for isolation and loneliness that they faced.

Individuals who resided with a co-habiting care partner turned to their partner as a primary source of social contact, and these relationships often facilitated further connections beyond the home.

However, for those participants living alone, municipal home care or day care services played a more crucial role in maintaining a degree of social interaction, an insight that supports existing studies (Eichler, Hoffmann, Hertel, Richter, Wucherer, Michalowsky, Dreier, & Thyrian, 2016; Lloyd & Stirling, 2014; Svanström & Johansson Sundler, 2015). The participants living alone wanted and actively searched for new social contacts and often used their local knowledge to identify 'hubs' within the neighbourhood where social opportunities would be most likely to exist. This could be as simple as finding the right bench to sit on during the summer-time. Indeed, benches had an important role to play beyond providing respite during a walk, they facilitated more opportunistic forms of social engagement and encouraged people to venture out of their home as a result (Otoni, Sims-Gould, Winters, Heijnen, & McKay, 2016). In Sweden, less attention has been paid by town planners and urban designers to the social function of such informal meeting places, but research in other countries has underlined their value for people in later life (Yen, Shim, Martinez, & Barker, 2012; Litwin & Shiovitz-Ezra, 2011). Another aspect of the social opportunities from our findings is the carefully manage proximal relations with neighbours. They were often kept at a distance and not considered to be a part of their social network. Ehn (1996) has shown that getting to know the neighbours, or to participate in social activities with them, was often not deemed a social necessity for many Swedish citizens, so this

may indicate a broader cultural trait. However, research on the value of neighbouring in other countries (Garoon, Engelman, Gitlin, & Szanton, 2016; Lapierre & Keating, 2013) points to its importance for people whose lives are focused at a local level. Hence, the creation of more meeting places in the neighbourhood could be beneficial for all older people, not only those people with dementia. Findings from the other fieldsites for the N: OPOP project show that neighbouring provides opportunities to maintain reciprocal relationships and stay connected to the most immediate social environment in which a person is located (Ward et al., 2017).

Those participants who had lived for many years in the same dwelling shared with us some of the benefits to ‘ageing in place’ which included their participation in a well-established and intergenerational local network. Indeed, there was evidence that GP’s had supported and advised some of the participants not to move following their diagnosis of dementia. The findings from our study correspond to the work from Rubinstein & Parmelee, 1992 and Rowles, 1983 which highlights how an older person’s attachment to places is closely entwined with their sense of self and identity.

Strengths and limitations

A particular strength of this study lies in the way that mobile methods, such as walking interviews were used to capture people’s lived experience of place and in this way to better understand the essence of neighbourhood for the participants. Walking interviews proved to be a particularly supportive method for involving people with dementia in research. This study, and the wider N: OPOP project are fairly unique in terms of using one-to-one walking interviews with people with dementia in this way to explore the meaning of neighbourhood. We would also

argue that our choice of method enhanced the credibility of our phenomenological approach (Lincoln & Guba, 1985). Analysis of the walking interviews was done together as a research group, and as such we were able to combine many years of experience of analysing qualitative data and knowledge of dementia research. This working process helped to enhance the trustworthiness of the findings. The description of the findings were supported with quotes from participants not only to gain a more direct understanding of their interpretations but also to aid efforts to judge the transferability of the data and findings to other contexts.

The study was situated in the county of Östergötland, and involved a fairly homogenous group with mostly men, all of whom were born in Sweden. We recognise this may limit any claims we can make from our findings, not least in respect to the experiences of a diverse population of people living with dementia. In Sweden the majority of women living with dementia are living alone (Svedem, 2016). This could explain why we had a gender bias toward men in our sample given that women with dementia may be less likely to have support from an informal care partner to participate in research. Despite this limitation, our experience points to the importance of recognising how gender shapes the experience and opportunities when living with dementia.

Implications for policy and practice

Our research shows that people with dementia actively integrate with the outside world if they are suitably supported to get out and about and this is important to consider from a dementia care perspective. It is clear that neighbourhood nursing (Cumberlege, 1986) has a crucial role to play in the development of dementia friendly communities (Mitchell & Burton, 2010) and that practitioners could enhance the support they offer to people with dementia by taking into

consideration a person's on-going capacity to access and move freely about the neighbourhood. We argue that the neighbourhood itself has to be a part of dementia care practice so that practitioners and local residents can collaborate in ways that enhance the inclusivity of public spaces and venues. Further, the findings reported here could make a significant contribution to an argument for the development of dementia friendly communities in Sweden. As yet, the potential for creating dementia inclusive and enabling communities is not widely appreciated in Sweden but our research clearly demonstrates the role of the local community in maintaining social connections and helping people with dementia to avoid isolation and the damaging effects of loneliness. Beyond health and social care services, the wider public and both local and national government all have a role to play in supporting people with dementia through the creation of walkable neighbourhoods, places with restorative potential and informal meeting places.

Conclusion

We have found that the neighbourhood for community-dwelling people with dementia holds a sense of attachment and offers freedom of movement. Our research indicates that a dementia diagnosis doesn't necessarily reduce the capacity to get out and about. The neighbourhood sustains a walkable area of life stories and plans for the future that people with dementia shared in the course of our walks together. The daily walks in the neighbourhood maintained social relationships and a restorative connection to nature for people living with dementia. We have to see the strengths neighbourhoods offer for people with dementia that enables ageing in place. The insights from our findings can teach us to see the meaning that neighbourhood holds for people with dementia from a wider perspective especially for those people living alone. Clearly, more

research is needed about the growing proportion of single householders with dementia and their opportunities to get outdoors and to maintain or foster new social connections.

Acknowledgment

We are grateful to the people with dementia who participated in this study and also acknowledge the contribution of the health care staff who helped with the recruitment of participants.

Declaration of conflicting interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This study was partly funded from the Swedish Riksbankens Jubileumsfond (grant number M10-0187:1). This work was supported by the Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR). The research forms part of Work Programme 4 of the ESRC/NIHR Neighbourhoods and Dementia mixed-methods study (reference ES/L001772/1; www.neighbourhoodsanddementia.org).

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Table 1. Demographic data over participants

Participant	Age (when the interview was done)	Sex	Type of dwelling	Year in the dwelling	Dementia diagnosis (year)	Marital status	Former occupation	Walking interview performed (year)	Aid during the walk
Anders	80	Male	Detached house-town	40	Alzheimer's disease Frontotemporal dementia (2012)	Married	Usher	2013	None aid
Anna	78	Female	Flat-town	3	Alzheimer's disease (2010)	Widow, single household	Factory worker	2016	Walker
Cecilia	78	Female	Flat- town	5	Alzheimer's disease (2010)	Widow, Single household	Machine minder	2013	Walker
David	75	Male	Detached house- rural	46	Alzheimer's disease Vascular dementia (2012)	Married	Joiner	2014	None aid
Fanny	87	Female	Flat-town	6	Alzheimer's disease (2013)	Widow, Single household	Nursing assistant	2014	None aid
George	79	Male	Flat-town	4	Vascular dementia (2013)	Married	Principal	2014	Walking poles
Ingvar	62	Male	Flat- town	20	Alzheimer's disease Vascular dementia (2012)	Unmarried, Single household	Author	2014	Walker
Jerker	68	Male	Flat-town	6	Alzheimer's disease (2013)	Partner	Factory worker	2014	None aid
Lennart	82	Male	Detached house-town	16	Alzheimer's disease (2010)	Married	Manager	2014	Walking with a dog
Nils	73	Male	Detached house- rural	50	Alzheimer's disease (2012)	Widower, living with a son	Joiner	2014	Walking poles
Per	77	Male	Flat-town	7	Alzheimer's disease (2011)	Married	Joiner	2014	None aid
Simon	79	Male	Detached house -town	15	Alzheimer's disease (2013)	Partner	Teacher	2014	None aid
Urban	81	Male	Detached house – town	50	Alzheimer's disease (2010)	Married	Teacher	2016	Walking poles
Yngve	74	Male	Terrace house-town	20	Alzheimer's disease (2010)	Partner	Factory worker	2016	None aid

