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Neighbourhoods as relational places for people living with dementia

Andrew Clark^{a,*}, Sarah Campbell^b, John Keady^b, Agneta Kullberg^c, Kainde Manji¹, Kirstein Rummery^d, Richard Ward^d^a School of Health and Society, University of Salford, Salford, Greater Manchester, UK^b School of Nursing, Midwifery and Social Work, University of Manchester, Manchester, UK^c Division of Community Medicine, Social Medicine and Public Health Science, Department of Medical and Health Sciences, The Faculty of Medicine and Health Sciences, Linköping University, Linköping, Sweden^d Faculty of Social Science, University of Stirling, Colin Bell Building, Stirling, UK

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ABSTRACT

An increase in the number of people living independently with dementia across the developed world has focused attention on the relevance of neighbourhood spaces for enabling or facilitating good social health and wellbeing. Taking the lived experiences and daily realities of people living with dementia as a starting point, this paper contributes new understanding about the relevance of local places for supporting those living with the condition. The paper outlines findings from a study of the neighbourhood experiences, drawing on new data collected from a creative blend of qualitatively-driven mixed methods with people living in a diverse array of settings across three international settings. The paper details some of the implications of neighbourhoods as sites of social connection based on material from 67 people living with dementia and 62 nominated care-partners. It demonstrates how neighbourhoods are experienced as relational places and considers how people living with dementia contribute to the production of such places through engagement and interaction, and in ways that may be beneficial to social health. We contend that research has rarely focused on the subjective, experiential and ‘everyday’ social practices that contextualise neighbourhood life for people living with dementia. In doing so, the paper extends empirical and conceptual understanding of the relevance of neighbourhoods as relational sites of connection, interaction, and social engagement for people living with dementia.

1. Introduction

This paper contributes new insight into how people living with dementia experience the places where they live, and how those places can support people to live as independently as possible with the condition. It presents analysis from an empirical, qualitatively-driven mixed methods study and outlines opportunities for social support facilitated by regular and habitual contact with others. Drawing on arguments about the relational nature of space, we add weight to calls to reconceptualise neighbourhoods as networked and relational rather than as fixed, physical or material entities. Recognising this relationality may provide opportunities to better appreciate the supportive capacity of local places for individuals living with dementia.

The relationship between ageing and one's local environment, including neighbourhood places, has long been of interest to social scientists and practitioners working in the field of dementia (Keady et al., 2012). As the “collections of settings older people frequent and move

between on a daily, weekly and monthly basis, such as their own homes, their friends' homes, family members' homes, retail locations and various formal care environments” (Andrews et al., 2013, p.1343), neighbourhoods are often considered crucial for enabling people to remain independent and active as they age (Wiles et al., 2009, 2011). Discourses around ‘dementia friendly communities’ and allied movements such as ‘age friendly cities’ are advancing theoretical understanding of, as well as policy and practice responses to, how people living with dementia can be better supported to live as well as possible (ADI, 2018; Herbert and Scales, 2017; WHO, 2017). However, we suggest that there remains a need to better understand how neighbourhood experiences can contribute to this, for example through engagement with localised social networks or remaining socially connected to enable better social health or wellbeing. This paper contributes to this understanding. It advances insight into the experiential meaning of local - or neighbourhood - spaces for people living with dementia. It explores how relationships, interactions and

* Corresponding author. School of Health and Society, University of Salford, M5 4WT, UK.

E-mail address: a.clark@salford.ac.uk (A. Clark).¹ Independent researcher.<https://doi.org/10.1016/j.socscimed.2020.112927>

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connections with others garner meaning in local contexts and might provide support to those living with dementia in the community. The paper considers these insights in the light of calls for greater appreciation of the relational geographies of everyday life and considers how neighbourhoods are places of possibility as well as restriction in the lives of people living with dementia. The paper ends by proposing ways in which a relational model of neighbourhood places might better support those individuals.

2. Living with dementia in neighbourhood settings

Where we age matters. Neighbourhoods are considered to be particularly important to the social health and wellbeing of older people, in part because changes in an individual's functional capacity may impact on mobility (Lawton, 1983) and because older people may experience greater sensitivity to the opportunities afforded by local places due to longevity of residence (Oswald et al., 2010; Rowles, 1978). Attachment to local places is also believed to strengthen as people get older as they become less mobile, less involved in outdoor activities, and see a shrinking of their social networks (Bowling et al., 1995).

Although ageing and dementia are not synonymous, the literature on ageing in place can inform how we might better understand the relevance of neighbourhoods to the lives of those living with dementia. For instance, and arguably intuitively, neighbourhoods are thought to offer an attractive system of support to enable or restrict a sense of wellbeing associated with being socially connected, promoting trust and cohesion through bonding and bridging social capital (Poortinga, 2012; Ziersch et al., 2005) and facilitating 'social health' by enhancing one's sense of active engagement and connectedness (Vernooij-Dassen et al., 2018). Social health has emerged in the dementia literature as a way of reframing experiences of the condition in ways that are less stigmatising. Rather than focusing on what individuals are unable to achieve, social health recognises that those living with a dementia can experience positive wellbeing through adaptation and maintaining a balance between opportunities and limitations in the context of social and environmental challenges (Huber et al., 2011; de Vugt and Dröes, 2017). Social health is thus considered a useful lens through which to maintain an awareness of the capacity of those living with dementia to participate in social life in meaningful and positive ways (Vernooij-Dassen and Jeon, 2016). Elsewhere we have assessed the potential for neighbourhoods to support the social health of those living with dementia (Ward et al., 2018). This paper adds further evidence of how environments outside of the home can enable individuals to fulfil their potential and obligations as citizens, interact with others, and participate more broadly in the social life of local places.

One way that neighbourhoods might be considered important to social health is through their roles as 'communities of place' and sites of social support and belonging. For instance, and while not concerned specifically with social health, Wiersma and Denton (2016) report on how social networks and informal social support were important for people to remain living in the community and locally engaged, so outlining an albeit fragile culture of care and looking out for each other that offers something of a safety net for individuals living with dementia. The idea of a 'shrinking world' has also been identified as particularly challenging for individuals living with dementia and their care-partners (Duggan et al., 2008; Kane and Cook, 2013). The importance of being able to go outdoors and consequently interact with the social and physical environment is thought to be central to an individual's ability to maintain wellbeing (Dröes et al., 2017) but living with dementia makes this increasingly difficult, in part because of associated cognitive as well as physical changes.

The last decade has witnessed some explicit interest in the role of neighbourhoods and communities of place for those living with dementia (e.g. Keady et al., 2012; Manthorpe and Iliffe, 2018). The dementia friendly community movement has developed globally through campaigns such as Alzheimer's Disease International that have

mobilised individuals, groups and organisation to actively shape (local) environments to suit the needs and aspirations of those living with dementia (ADI, 2018). Although not exclusively geographically-situated, dementia friendly communities have tended to adopt a geographical slant, promoting the development of local places to better enable people living with dementia to have more choice and control over their lives and to remain independent for as long as possible (Alzheimer's Society, 2013, 2014). Here, work to promote dementia friendly and dementia-enabling environments has focused on the development of good design principles, such as consideration of how the outdoor environment can be adapted to enhance people's ability to successfully enter and navigate their local neighbourhoods (Mitchell et al., 2003; Mitchell and Burton, 2006).

However, efforts to promote 'dementia-friendly communities' have not gone unchallenged. Aspirations toward 'friendliness' has been argued to underplay questions of rights and entitlements against a backdrop of austerity and widespread cuts to health and social care budgets (Shakespeare et al., 2017). Under the banner of dementia friendly communities, commentators have begun to question the positioning of dementia as exclusively the domain of health and social care, arguing that "it is the daily attrition of everyday life where help is most needed. People with dementia and family carers find routine activities most difficult - shopping, managing finances, using transport, keeping active - causing them to withdraw and impacting upon their well-being" (Crampton and Eley, 2013, p.49). Consequently, dementia has become an emerging concern in fields as diverse as business and retail (Borsson et al., 2018; Edwards et al., 2018), tourism (Connell et al., 2017), transport studies, (Risser et al., 2015), town planning (Biglieri, 2018), financial management (Giebel et al., 2018) and sport and leisure (Fortune and McKeown, 2016). This move towards a more multi-disciplinary terrain points not only to a re-spatialising of dementia, shifting focus from institutionalised settings, but also a break with constructions and understandings of dementia exclusively according to health and social care discourses and priorities (Hillman and Latimer, 2017, Thomas and Milligan, 2018).

The research reported in the rest of this paper takes as its starting point the experiential realm of what it means to venture into and interact with others in a location loosely termed a neighbourhood from the perspective of individuals living with dementia. In appraising how individuals construct and engage with their socially-experienced neighbourhoods, we outline the importance of understanding such places as relational, rather than a Euclidean or zonal phenomena implied by cartographic representations (Massey, 2005). Our aim is not to assess how the material or built environment can better support people to navigate the physical environment, nor to evaluate how changes in cognitive function can reduce the opportunities for going outdoors. Rather, it is to provide insight into the ways in which neighbourhoods can act as locations for social connectivity, and outline some of the ways in which this can enable people living with dementia to feel sufficiently supported to maintain a sense of belonging in ways that might be conducive to social health. We also contribute new knowledge about the active role people living with dementia can play in developing sustainable, dementia-appropriate environments.

3. Approach and methods

The data reported was gathered as part of a 5-year, international work package that forms part of a larger research programme on neighbourhoods and dementia. The research is collecting and analysing data in an iterative and qualitative-driven mixed method design framed by a participatory ethos and constructivist paradigm. It focuses on the phenomenological and interpretive dimensions of the meanings neighbourhoods holds for participants as well as their day-to-day neighbourhood-related practices. The research aims to understand how neighbourhoods support the well-being and everyday lives of people with dementia and their carers in order to understand how such places

can be better appreciated and developed as sites of support and engagement.

Rather than impose our own predetermined definition of what may, or may not, constitute a neighbourhood we focused the subjective interpretations offered by participants and which we sought to understand through a threefold set of methods. One, walking interviews involved people living with dementia and sometimes their family carers taking us on a 'neighbourhood walk' and to show us around their local area. Participants told us about their memories of living there, and we asked about their different connections to the place. We also enquired about what they like, or do not like, about where they live (see also Clark, 2017). Second, in the UK sites, we made use of filmed home tours (Pink, 2009). We considered home as the starting point to the neighbourhood and were interested in what 'home' means to the participants. Participants were invited to take the researchers on a filmed tour around their home, telling us about how they spend their time at home and what was important to them about their home. Finally, we adopted a participatory network mapping technique, asking family carers and people living with dementia (whenever possible) to tell us about the relationships that they have in their everyday lives. We asked participants to 'map' and describe these relationships and to tell us about any support that they give and receive (Campbell et al., 2019). Ethical approval was obtained across the three field sites, in Sweden and Scotland by the respective institutional ethical review boards and in England by the NHS health and social care ethics committee through IRAS (REC Reference: 15/

Data collection took place across the central belt of Scotland, Greater Manchester in north-west England, and the county of Östergötland in Sweden. Although conscious of what Emmel (2013) refers to as a linguistic fallacy of reducing our sample to a set of quantifiable markers, our combined cases comprise of 129 individuals who live in city, suburban and rural locations, come from a variety of different backgrounds, and live with different types of dementia. The extent and form of the data collected is detailed in Table 1. Interview data was transcribed verbatim. Transcripts were read several times by team members alongside the viewing of visual materials produced during the interaction and subjected to a thematic coding framework that was developed iteratively with analysis moving between data and existing literature.

4. Findings: neighbourhoods connections and networked neighbourhoods

4.1. Neighbourhoods as connections

While individual experiences are unique the data demonstrates how subjective feelings about a neighbourhood can be a significant source of support and contribute to an individual's wellbeing, for example with respect to social interaction, participation and engagement (Wahl and

Weisman, 2003; Wiles et al., 2009). Our data reveals neighbourhoods to be important in two ways; for the provision of practical support, goods and services that can be used and consumed to sustain life; and for the development of relationships and interactions that are key to maintaining a sense of connection. Connections may develop across a lifetime of living in one location (that is, as connections to place) or because of the relationships we form with others living and working there (as connections to people). Both are central to the ways in which people living with dementia experience and think about the neighbourhoods where they live, and both contribute to a sense of belonging through their active production of neighbourhood places.

Participants describe a diverse and complex range of different forms and functions of locally situated connections. These include close and distant family; different friendship groups; neighbours; local shop keepers; service providers; and passers-by. These connections can provide a form of support in different ways and for different purposes, though it is important to recognise that it is not a question of 'how many people' someone with dementia may know that matters, but rather the quality of those relationships, and the capacity for such relationships to provide different types of timely support. For instance, and as we have argued elsewhere (Ward et al., 2018), one group of individuals that have emerged as being important have been neighbours. Such individuals provide emotional and practical support, and importantly, also offer a 'watchful eye' and a feeling of being connected to a wider social sphere. Many participants were able to point to at least one instance of how a neighbour was able to offer some form of support. This included the management of household waste, such as 'putting out/bringing in of rubbish bins [or trash cans], taking in parcels, looking after pets, properties and gardens when residents were away, and keeping an eye out for anything untoward. Participants also identified good neighbourly practices:

"She makes pancakes and passes the baking over the fence. She's a nice wee neighbour." (Anne, Scotland)

"[the people who live] next door are brilliant. I might not see them from one day to the next, but my daughter has got their phone number and they take my [rubbish] bins out and bring them back for me whenever they need emptying" (Margaret, England)

"[people living round and about] are so nice, a good sort really, you know, I can talk to anyone here" (Anders, Sweden)

'Familiar strangers' also contribute a sense of support. These individuals may be encountered on a regular basis but whose personal details, such as their name or where they live, remain unknown. June for example, visits a shop almost daily, ostensibly to collect a newspaper for herself and occasionally a neighbour:

"Yes. I like the crossword in the [newspaper]. I do my crossword every morning with me first cup of tea."

Table 1
Scope and scale of data set.

		England	Scotland	Sweden	Total
Participants	Total	56	47	26	129
	Living with dementia	29	22	16	67
	Nominated care-partner	27	25	10	62
	Living in couple dyad	44	15	10	69
	Living alone/alternative arrangement	12	7	6	25
Age (of person living with dementia)	Youngest	57	51	62	
	Oldest	88	88	87	
Methods	Network maps	47	30	30	107
	Walking interviews	37	16	18	71
	Home tour	30	27 (not all filmed)	0	57
	Total	114	73	48	

Researcher: So do you get the paper every day?

Everyday, yeah." (June, England)

June's visit to the shop matters because it maintains a connection with a wider world. Her frequent visits enable staff to recognise her and, as she told us, look out for her, helping her count her change after her purchases and ensuring she is keeping well. Such exchanges are short lived but their lasting impression, at least for June, means that she feels connected to a part of a broader network of individuals. Indeed, when June was too unwell to make her regular trip to the store an employed delivered the paper to her home. John outlined a similar sense of familiarity with staff at a shop he visits regularly:

"I went into the local shop. I go in there for a paper ... I said, I'm going to tell you that I've been diagnosed with dementia. 'Oh, God', she says, 'That's a shame. Well', she says, 'I'll have a talk to the [staff] and just tell them to look after you'." (John, Scotland)

Acts of kindness are built on the recognition that comes from routine and are brought to the fore at times of potential concern. Doreen recalled a time when she became disorientated when on a routine walk:

"I still enjoy walking. That's why I lost myself, I kept walking, and walking, and walking and just forgot where I was, and somebody was going past and says to me, 'Doreen, where are you going?' And I'm thinking, why is this person asking where I'm going?... I was just walking ..."

Researcher: So people knew you where you were?

Yeah, in the area, yeah.

Researcher: So people had looked out for you?

Oh yes, yeah." (Doreen, England)

Being recognised in local shops also offers an important sense of belonging in place:

"Researcher: So the lady recognised you?

Yes! It's been quite some time, but yes, she does recognise me ... And it's so nice to come into places, and be greeted, you know, 'I haven't seen you for some time, and how are you?' Yes, it's really nice, I do appreciate that." (Viv, England)

"I was out on a walk one day and I was going to go to the little shop ... and I don't know for what reason, but ... I couldn't remember how I should get to the shop, and I had to stop the man and say, excuse me, can you tell me where that little grocer's shop is, I've got dementia, and I'm a bit lost, so he very kindly directed me ... and I think that was a good thing to do, because it's like public education as well, don't hide it, just say." (Judy, Scotland)

Repeated, regular acts of recognition enable connections to both people and place. Visible presence, fleeting recognition, familiar strangers, and seeing others and being seen in particular spaces at particular times are all central to how participants engaged with a wider social sphere and enable participation in what Jacobs (1961) called the 'street ballet' of urban life. Being recognised by familiar strangers facilitates a sense of connection and, we would add, a belonging to, place by participating in the social life of small urban spaces (Morgan, 2009). Such connections are made through the routine, mundane interactions with, for example, staff in local stores, cafes and on public transport, as well as passers-by, among whom a moment of recognition through a passing hello, smile, nod of the head or even brief eye contact matter because they symbolise, and embody, recognition and belonging in place. Shallow or informal neighbourhood interactions can range from the subtlety of a smile through a window or an acknowledgement of presence when passing by, through to clear recognition and a stop for a chat on the street (Blokland, 2003; Harris, 2008). They may also be more significant in terms of social capital than

is generally recognised, enabling participants to connect with a social environment than can stretch beyond the social capital available through weak ties (Granovetter, 1973). Neighbourhoods have the potential, then, to not only act as sites for information and social interaction, but also exist as relational webs of support; metaphorical safety nets available in exceptional circumstances. Indeed, neighbours appear to be a key source of immediate support because of their geographical proximity to offer assistance at short notice.

While local social connections can play an important supportive role for those living with dementia, such support is not unidirectional. People living with dementia are active players in a wider web of interconnections, providing support to other members. This can include caring for a partner, grandchildren or ageing parents or friends, as well as looking out for neighbours and others close by. Participants described engaging in 'small acts of kindness' (Anderson et al., 2015) for friends and neighbours, running errands, or keeping an eye on property when people go away. Such acts are conducted without reciprocal obligation and can be a socially complicated process. Importantly they indicate how people living with dementia play important roles in supporting and caring for others and have the capacity to engage in acts of reciprocity.

4.2. Networked neighbourhoods

Our findings support previous work about the role of local social support networks available to people living with dementia (Wiersma and Denton, 2016). It also indicates how neighbourhoods might still be understood as geographically proximate locations bounded by how far one can easily travel or walk (Blackman et al., 2003; Keady et al., 2012). Yet this is not the only, or perhaps even most 'realistic' or authentic, way of understanding the neighbourhoods our participants encounter and engage with. As Andrews et al. (2013) explain, Doreen Massey (1991, 1999; 2005) has argued that such views may produce rather uncritical, homogenous and exclusionary views of neighbourhood places that ignore the power geometries that shape both them, and the lives of those who experience them. 'Time-space compression' means that places are no longer the product of local processes, institutions and actions, but are rather produced by global forces. The result is a reconceptualization of local places as compressed and stretched-out entities experienced at different scales by different social groups.

Neighbourhoods are not static plains within which activities take place and relationships form. Nor are they clearly bounded units that expand and contract according to an individual's ability to get out and about. Rather they are experienced, and are revealed to us, as a series of networked locations connected through paths and lines of travel, be that through the regular tread of feet on pavement, a bus or cab ride, or lift in a car. For example, one husband explained how his wife (who lives with dementia) makes a weekly trip to a nearby town, catching a bus there and back on her own:

"She knows where she's going, she's got a phone with her. There's three buses and they all go to the same place, all the same way. If she sees the precinct, she gets off for the shops, and she knows where to get the bus back. So it's a very short walk to the bus stop, it's a very short walk home, so ... that gives her a little bit of independence, you see." (David, England)

Regularity and routine appear central to the production of networked neighbourhoods and the support they may be able to provide as those living with dementia maintain a sense of familiarity with and, to a lesser degree, confidence in, navigating through space, to remain as independent as possible (Bartlett and Brannelly, 2019). For June, a fortnightly visit to a relative allows her to maintain a sense of independence, for example by grocery shopping in a large supermarket some distance from where she lives (see also Ward et al., 2018), while for others, neighbour-relations are central to maintaining a connection

to a poignant sense of belonging:

“The bus stop there will take me to [town] and the bus stop on the other side I can go all the way to the Shopping Centre if I want and my sister-in-law lives in between [here and there]. And because I’ve been doing it from my own home I am used to catching the same bus. I can do that blindfolded. I don’t go anywhere else on the bus, but I can go to her house. I can do that no problem ... I’ve done it for so long it’s like going to the corner you know.” (June, England)

“[Neighbour] has a car and so, because I do not have a car anymore ... But I’ve stopped [driving] and ... so we socialize, and I can go with him and so, so it’s great and we have our loved ones in the cemetery in [a nearby town] and so we go there sometime”. (Fanny, Sweden)

Common to these experiences is a sense of familiarity not simply in terms of recognising the places that are passed through on the journey, but also in engaging in the routine of visiting or passing through the same location at the same time, using the same mode of travel. So, the capacity for familiarity, recognition and belonging that we noted earlier means that those places further away from home might be considered just as ‘local’ as spaces closer to home as neighbourhood experiences becomes stretched across space.

In some cases, these stretched-out neighbourhood spaces cover much greater distances with the aid of technology such as skype and internet messenger services. Occasionally, such technology is used to mediate local interactions over distance:

“I suppose the biggest person that is a support to me is a girl called [name]. And she’s my best friend and I talk to her every day. She texts me in between times, she WhatsApp’s me ... They live in Dubai. So yes, it’s not easy to have a coffee with [her] but we talk every day and if she’s worried about me she’ll organise a haircut for me, I just turn up at the hairdressers and it’s already been paid.” (Brenda, Scotland)

Two participants who had migrated to the UK remained in regular contact with relatives in Africa and the Caribbean through communication technologies, and notably, with the support of family members who acted as digital proxies through which messages could be passed. Both also maintained connections with acquaintances who had also migrated to the UK and maintained cultural links through regular visits to a barber shop that specialised in cutting African and Caribbean men’s hair, as well as attending specific community groups providing culturally relevant activities. Crucially, such activities and services were not located within the immediate geographies of participants’ local neighbourhoods, but required a degree of travel and planning, mostly with the support of family members, to attend them and maintain the connections.

The use of public and private transport, as well as communication technologies, make for a more relational sense of neighbourhood engagement for our participants. Consequently, and although conscious of avoiding the conflation of social networks with neighbourhood support, we suggest that as social locations neighbourhoods are experienced as a series of contracting and expanding networked phenomena (Massey, 2005) rather than geographical zones bounded and determined by how far an individual can walk.

However, local ties have not been rendered irrelevant or redundant. It is important to recognise that the local scale becomes important again as the condition changes, in part because of the embodied nature of daily life. Neighbourhoods remain paramount for those living with dementia who may be predominantly situated, or even fixed, in domestic environments or resigned to specifically designated ‘dementia-friendly’ communities, or for those who live alone and have less direct support from other members of a household (Odzakovic et al., 2019). Our analysis has identified elements of the ‘shrinking world’ outlined by Duggan et al. (2008) that can fuel this narrative. Participants described greater anxiety leaving the home independently, sometimes because of a deterioration of the cognitive capabilities associated with dementia,

such as memory loss, confusion, and spatial disorientation, or a loss of confidence in being able to cope in challenging circumstances, such as becoming lost. It is important not to romanticise, or celebrate, the power of the local to enable participants to live a ‘good life’ with dementia or dismiss the idea of a shrinking world as irrelevant. Elizabeth for instance had begun to experience difficulties going to a nearby gym on her own:

“One of the worst things for me is, because my memory can go ..., we can walk along and it can just go off. And there’s been times when I’ve gone into town and then I’ve had to phone [husband] and say, what bus do I get home? And he’s like, right, stay there, I’ll come and pick you up. And there was one time when I did it, he said, where are you? I said, well, I’m in town and I forgot where I am. And he said, ‘right, well, get a taxi ... I will feel safer knowing that you’re at home, you know’. So this is a problem in some situations. I don’t go to the gym on my own because although they know I have the dementia, I don’t want [pause] you have to start thinking in advance of things.

Elizabeth’s husband and main care-giver: But you’ve also got to have a certain point of independence.

You’ve got to have independence, but you also have to think, I can’t do this, or if I do this, if I go to the gym and I have a ... memory lapse or something like that, that then puts the onus on them in the gym. And it’s not fair ... to my mind, it’s not fair on them You don’t want to be a burden to somebody. I went in one time, when [husband] was locking the car and I’d gone in, and the girl at the counter said, ‘oh, are you on your own?’ I said, ‘no, you don’t have to worry, [husband is] coming now’, you know. And you could see her thinking”. (Elizabeth, England)

Others talked of growing isolation caused by the physical distance between themselves and their friends and family:

“It’s just with my family not living locally and things like that. You feel a bit lonely, especially when I see people coming, people coming to visit with their family, and [neighbours] go out and visit their family because they live locally and that sort of thing ...

[later]

Researcher: But nowadays you don’t really tend to go out on your own then?

Not really, because, I mean, my family don’t live locally. I can’t even remember where I live and where I don’t live.” (Doreen, England)

Of course, the neighbourhoods that our participants experience are also changing. Moving away of neighbours, friends and family, the closure of a shop or local resource, or even the changing of the seasons could all result in participants experiencing difficulties continuing to maintain a sense of familiarity which can enable belonging. Alternatively, at a point when dementia might make it difficult for individuals to venture far from home, we are reminded of the importance of local connections and the opportunity to see neighbours come and go, watching passers-by from balconies and watching the comings and goings of the street outside through the window or from a front porch have particular salience (Odzakovic et al., 2019). For instance, over the course of the research Violet became too unwell to leave her home. She increasingly came to value sitting in her wheelchair by her front door:

“When I feel like it ... I sit outside.

Researcher: In your garden?

Yes. I sit on the drive and ... [watch] children go up [the road].

Researcher: Do they?

Yes. And I see them

Violet’s husband and main care-giver: There’s one who lives opposite and he brings all the school kids with him.

Researcher: Does he? And he comes over for a chat?

Violet's husband and main care-giver: They come over just now and again, you know.

Researcher: Do you like that when the kids come over and chat with you?

Oh yeah, yeah. I enjoy it. I enjoy children talking ... I like to tell them about when I was a child, you know? I had a good life." (Violet, England)

Violet strives to articulate here the importance of local connections that reach beyond the more formalised relationships people have with family and friends. It is notable that the connections Violet talks about are embodied as well as biographical. It matters to her that she can see and hear children pass by the end of her driveway, and their doing so serve as a reminder of previous times. Implicit here is the ways in which neighbourhoods serve as points of connection, not just through a physical connection to services and facilities, but also a social connection to a wider world.

5. Discussion: what do neighbourhoods mean for people living with dementia?

Our data and analysis provide a twofold contribution to the broadening of our understanding of neighbourhoods. First, there is an ongoing relevance in thinking about neighbourhoods as more than physical entities in the literature on dementia and the environment. While this may not be revelatory to those familiar with debates about ageing in place, it is important that those working in allied fields, such as dementia, also take stock. Certainly, neighbourhood physicality is important, and we do not intend to dismiss as irrelevant work on the modification of the built environment to better support those living with dementia. Nonetheless, neighbourhoods remain socially experienced phenomena. They are the locations where daily life is produced through interaction and relationality. Our analysis highlights the importance of taken for granted, perhaps overlooked, routines and habits that can contribute to wellbeing. Sources of mundane interaction and ordinary encounter can enable individuals to feel connected to a wider network, and thus contribute, albeit subjectively, to a sense of belonging in, and through, place (Anderson et al., 2015; Cattell et al., 2008). The types of interaction that we have reported on here arguably contribute to this process, not through the provision of direct or demonstrable support, but rather by helping people to feel comfortable through the creation of loose ties through nods and smiles of recognition. Recognition goes beyond the reciprocal value of bridging and bonding capital to enable a sense of situated belonging among familiar and intimate strangers (Morgan, 2009; Perren et al., 2004). Echoing May and Muir (2015), we suggest that it is not so much the practical support provided by neighbours or emergency assistance offered by passers-by that matter but rather how incidental encounters of all sorts contribute to a sense of attachment to neighbourhoods.

Second, neighbourhoods are not static or remain immune to change but are shaped by people and their practices. Yet "too frequently, there is a tendency to treat "place" simply as a context ... rather than seeing it as productive of particular outcomes for older adults, as well as being shaped by them" (Andrews et al., 2007, p.12). Blackman (2006) suggests that the neighbourhood may represent the smallest socio-spatial scale at which public life unfolds, and that an understanding of how people experience and define their neighbourhood is thereby crucial in recognising the role it plays in supporting their health. For Blackman, the neighbourhood can be experientially identified "as we leave our front door. Where it ends varies according to many spatial and temporal factors but, in public health terms, the concept of a walkable zone of experience is important" (2006 p.33). Although a useful starting point, this definition should be broadened in ways that capture not only the locational but also the affective and relational meanings of neighbourhood to residents.

Our work demonstrates how ageing in place with dementia is a broad concept of meaning beyond practical and functional issues. It shows how neighbourhoods are constituted as relational entities where a sense of place emerges through "connections within networks of 'translocal interactions', related to and produced by many other spaces and places at multiple scales". (Anderson et al., 2013; p1348). A neighbourhood is more than a walkable zone within which dementia-appropriate services and assistance can be offered. Rather it constitutes a networked location of, at times contraction, and at other times, expansion. While such fluctuation is subject to and the result of, changes in the dementia condition, it is also due to the dynamic nature of relationships that are formed within, and transcend, place. We are not suggesting that our participants are experiencing the globalized, cosmopolitan neighbourhoods that were the impetus for Massey (2005) conception of a global sense of place. Rather, the encounters and connections that inform relational places for participants constitute what Andrews et al. (2013, p1345) define as mutually constituted processes of making people and places, starting with the process of 'embedded knowledge' that can be gained through encounters with place through direct immersion, direct encounter, and in the case of transport and technology, through connection at a distance. In the context of living with dementia, neighbourhoods need to be understood as relational sites of familial and social recognition and interaction, as well as habitual, routine practices engagement. This enables us to see neighbourhoods as local places, not in terms of physical locations of scale of walkability (for instance), but rather sites that transcend geography to enable habitual practices, familiarity and social interconnectivity to be enacted across multiple sites and scales.

There are two caveats to this argument. First, the experiences we have sought to understand have come from multiple locations, revealed to us as individual rather than collective experiences. They thus remain deeply subjective accounts that, perhaps, might even mask some of the vulnerabilities our participants might experience when going outdoors (Bartlett and Brannelly, 2019). Certainly, neighbourhoods can still be understood as collective experiences, and the development of dementia friendly communities offers one way of enabling people living with dementia to reproduce neighbourhoods in ways more suited to their requirements and aspirations. Second, we are cautious to avoid producing an overly optimistic or joyful collection of experiences that eradicate the different, at times difficult, experiences of those living with dementia. For it is possible to construct a narrative of decline in local places, either as a consequence of changes brought on by the condition that limits an individual's ability to get out and about, or because of a sense of malaise over lost communities and a breakdown in local ties. However, people living with dementia have not fallen passive victims to this process. They continue to make and maintain different forms of connections locally, and they are also part of the processes that are creating new connections that stretch across space and that "can be imagined as articulated moments in networks of social relations and understandings" (Massey, 1991, p.28).

6. Conclusion

This paper has proposed new avenues for thinking about how people with dementia understand and experience the locations where they live. While there is still work to be done to develop and assess the ideas we have presented, we hope this paper goes some way to widening our understanding of, and furthering debate about, the links between dementia, neighbourhoods, and even ageing in place more broadly. We have made two points with respect to this. First, people living with dementia play active roles in the ongoing production and maintenance of neighbourhoods as interconnected, relational places. And second, being socially connected to neighbourhoods constituted in this way affords opportunity to remain engaged.

Two further implications emerge from this. First, staying connected highlights for many of our participants the importance of interactions in

terms of on-going communications, and non-verbal signs of recognition, as well as the possibility to see others and be seen themselves. We concur with Anderson et al. (2015) assessment of the merits of engaging in 'little acts of kindness'. Such acts are frequently and routinely carried out by neighbours and other 'familiar strangers' without comment and enable people to continue to live independently. While there has been discussion about the different roles that interactions with non-intimates assume (Lofland, 1998; Morgan, 2009), our research begins to demonstrate how individuals living with dementia also assume these roles, and also carry out acts of support and contributing to social connectivity. Such reciprocity implies that people living with dementia can continue to play an active role in their neighbourhoods, contributing to, as well as drawing upon, local spaces as inter-connected webs of support (Wiersma and Denton, 2016). Our analysis suggests that the opportunity to go outdoors and remain a part of the social life of small spaces is beneficial. This is not just because of the physiological and psychological benefits of being able to go outdoors per se, but also because it allows for the opportunity to engage in serendipitous, as well as planned for, interaction with others. Our findings advance the social health literature (Vernooij-Dassen et al., 2018) as well as earlier work on wellbeing (e.g. Cattell, 2012). Being connected to others as part of a wider system of people and places can in turn offer a metaphorical safety net of support to call on should the need arise. Engaging in regular or routine journeys, frequenting the same shops, and knowing, however slightly, one's neighbours can all enable this to happen, but it requires a conscious effort on everyone's part to be open to the possibilities of encounter and interaction, irrespective of whether we are living with dementia. More significant for those living with dementia, casual but regular encounters in neighbourhood spaces may go some way to raising awareness of the condition and reducing some of the stigma displayed by those with limited experience of the condition.

The second implication concerns how neighbourhoods are conceptualised in health and social care practice. The convenient but imprecise term 'neighbourhood' takes for granted assumptions about the seemingly geographically limited, tightly bounded spaces within which people live. Our analysis indicates a need to further explore the meaning of 'neighbourhood' through a relational lens in the context of dementia. Neighbourhoods are more than containers of practical support. They can potentially offer opportunities for people living with dementia to actively engage in processes that shape spaces in meaningful ways. In the construction and maintenance of connections to people and places we see the development of a more networked or relational sense of place. Here, the active engagement of people living with dementia in the social production of neighbourhood spaces should not be overlooked.

Individuals living with dementia inevitably experience their neighbourhoods in different ways, and at times the symptoms of dementia may impact on the nature of this experience. Yet so too will other circumstances, including co-morbidities, age, gender, from household composition, existing social networks, and the length of time spent living in a place. This paper offers a contribution to understanding some of this complexity. Going forward, there is a need for research to better understand the importance of a relational sense of place for those living with dementia, and how this intersects with fluctuations in the condition, to appreciate a more nuanced awareness of the ways in which neighbourhoods can support, as well as at times inhibit, life for those with dementia.

Declaration of interest

None declared.

Ethics approval

Ethical approval was obtained across the three field sites, in Sweden and Scotland by the respective institutional ethical review boards (see

author affiliations for details) and in addition, in England by the NHS health and social care ethics committee through IRAS (REC Reference: 15/IEC08/007).

CRedit authorship contribution statement

Andrew Clark: Conceptualization, Investigation, Formal analysis, Writing - original draft, Writing - review & editing. **Sarah Campbell:** Investigation, Formal analysis, Writing - review & editing. **John Keady:** Writing - review & editing. **Agneta Kullberg:** Investigation, Formal analysis, Writing - review & editing. **Kainde Manji:** Investigation, Formal analysis, Writing - review & editing. **Kirstein Rummery:** Writing - review & editing. **Richard Ward:** Conceptualization, Investigation, Formal analysis, Writing - review & editing.

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References

- Alzheimer's Disease International, 2018. Dementia Friendly Communities: Key Principles. Retrieved from. <https://www.alz.co.uk/dementia-friendly-communities>, Accessed date: 1 September 2018.
- Alzheimer's Society, 2013. Building Dementia Friendly Communities: A Priority for Everyone. Alzheimer's Society, London.
- Alzheimer's Society, 2014. Foundation Criteria for the Dementia Friendly Recognition Process. Alzheimer's Society, London Retrieved from. https://www.alzheimers.org.uk/sites/default/files/2018-06/DFC%20Foundation%20Criteria_Fs%20Albert_4.pdf, Accessed date: 1 September 2019.
- Anderson, S., Brownlie, J., Milne, E.-J., 2015. Understanding Everyday Help and Support. Joseph Rowntree Foundation, York Retrieved from. <https://www.jrf.org.uk/report/understanding-everyday-help-and-support>.
- Andrews, G., Cutchin, M., McCracken, K., Phillips, D., Wiles, J., 2007. Geographical gerontology: the constitution of a discipline. *Soc. Sci. Med.* 65 (1), 151–168.
- Andrews, G.J., Evans, J., Wiles, J., 2013. Re-spacing and re-placing gerontology: relationality and affect. *Ageing Soc.* 33 (8), 1339–1373.
- Bartlett, R., Brannelly, T., 2019. On being outdoors: how people with dementia experience and deal with vulnerabilities. *Soc. Sci. Med.* 235. <https://doi.org/10.1016/j.socscimed.2019.05.041>.
- Biglieri, S., 2018. Implementing dementia-friendly land use planning: an evaluation of current literature and financial implications for greenfield development in suburban Canada. *Plann. Pract. Res.* 33 (3), 264–290.
- Blackman, T., 2006. Placing Health: Neighbourhood Renewal, Health Improvement and Complexity. Policy Press, Bristol.
- Blackman, T., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S., Williams, K., 2003. The accessibility of public spaces for people with dementia: a new priority for the 'open city'. *Disabil. Soc.* 18 (3), 357–371.
- Blokland, T., 2003. Urban Bonds: Social Relationships in an Inner-City Neighbourhood. Polity Press, Cambridge.
- Bowling, A., Farquhar, M., Grundy, E., 1995. Changes in network composition among older people living in inner London and Essex. *Health Place* 1, 149–166.
- Brorsson, A., Ohman, A., Lundberg, S., Nygard, L., 2018. How Accessible Are Grocery Shops for People with Dementia? A Qualitative Study Using Photo Documentation and Focus Group Interviews. *Dementia* 1471301218808591.
- Campbell, S., Clark, A., Keady, J., Kullberg, A., Manji, K., Rummery, K., Ward, R., 2019. Participatory social network map making with family carers of people living with dementia. *Methodol. Innovat.* 12 (1).
- Cattell, V., 2012. Poverty, Community and Health: Co-operation and the Good Society. Palgrave Macmillan.
- Cattell, V., Dines, N., Gesler, W., Curtis, S., 2008. Mingling, observing and lingering: everyday public spaces and their implications for well-being and social relations. *Health Place* 14, 544–561.
- Clark, A., 2017. Seeing real life? Working with the visual to understand landscapes of community. *Int. Rev. Qual. Res.* 10 (2), 190–210.
- Connell, J., Page, S., Sheriff, I., Hibbert, J., 2017. Business engagement in a civil society: transitioning towards a dementia friendly visitor economy. *Tourism Manag.* 61, 110–128.
- Crampton, J., Eley, R., 2013. Dementia-friendly communities: what the project "creating

- a dementia-friendly York" can tell us. *Work. Older People* 17 (2), 49–57.
- Dröes, R., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., Verbeek, H., Vernooij-Dassen, M., Clare, L., Johannessen, A., Roes, M., Verhey, F., Charras, K., the Interdem Social Health Taskforce, 2017. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging Ment. Health* 21 (1), 4–17.
- Duggan, S., Blackman, T., Martyr, A., Van Schaike, P., 2008. The impact of early dementia on an outdoor life: a shrinking world? *Dementia* 7 (2), 191–204.
- Edwards, K., Rosenbaum, M., Brosdahl, D., Hughes, P., 2018. Designing retail spaces for inclusion. *J. Retailing Consum. Serv.* 44, 182–190.
- Emmel, N., 2013. *Sampling and Choosing Cases in Qualitative Research: A Realist Approach*. Sage, London.
- Fortune, D., McKeown, J., 2016. Sharing the journey: exploring a social leisure programme for people with dementia and their spouses. *Leisure Sci.* 38 (4), 373–387.
- Giebel, C.M., Flanagan, E., Sutcliffe, C., 2018. Predictors of finance management in dementia: managing bills and taxes matters. *Int. Psychogeriatr.* 31 (20), 277–286.
- Granovetter, M.S., 1973. The strength of weak ties. *Am. J. Sociol.* 78 (6), 1360–1380.
- Harris, K., 2008. *Neighbouring and Older People: an Enfolding Community?* Community Development Foundation/Age Concern, London.
- Herbert, C., Scales, C., 2017. Dementia friendly initiatives: a state of the science review. *Dementia* 10 1177/1471301217731433.
- Hillman, A., Latimer, J., 2017. Cultural representations of dementia. *PLoS Med.* 14 (3), e1002274.
- Huber, M., Knottnerus, J., Green, L., van der Horst, H., Jadad, A., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M., van der Meer, J., Schnabel, P., Smith, R., van Weel, C., Smid, 2011. How should we define health? *British Med. J.* 343 (d4163). <https://doi.org/10.1136/bmj.d4163>.
- Jacobs, J., 1961. *The Death and Life of Great American Cities*. Pimlico, London.
- Kane, M., Cook, L., 2013. *Dementia: the Hidden Voice of Loneliness*. Alzheimer's Society Retrieved from www.alzheimers.org.uk/dementia2013.
- Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., Burrow, S., Elvish, R., 2012. Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development. *Rev. Clin. Gerontol.* 22, 150–163.
- Lawton, M., 1983. Environment and other determinants of well-being in older people. *Gerontol.* 23, 349–357.
- Lofland, L.H., 1998. *The Public Realm: Exploring the City's Quintessential Social Territory*. Aldine Transaction, New Brunswick.
- Manthorpe, J., Iliffe, S., 2018. Muddling along in the city: framing the cityscape of dementia. *Dementia* 10 1177/1471301218817451.
- Massey, D., 1991. A global sense of place. *Marxism Today* 38, 24–29.
- Massey, D., 1999. Spaces of politics. In: Massey, D., Allen, J., Sarre, P. (Eds.), *Human Geography Today*. Polity, Cambridge, pp. 279–294.
- Massey, D., 2005. *For Space*. Sage, London.
- May, V., Muir, S., 2015. Everyday belonging and ageing: place and generational change. *Socio. Res. Online* 20 (1), 1–11.
- Mitchell, L., Burton, E., 2006. Neighbourhoods for life: designing dementia-friendly outdoor environments. *Qual. Ageing* 7 (1), 26–33.
- Mitchell, L., Burton, E., Raman, S., Blackman, T., Jenks, M., Williams, K., 2003. Making the outside world dementia-friendly: design issues and considerations. *Environ. Plann. Plann. Des.* 30 (4), 605–632.
- Morgan, D., 2009. *Acquaintances: the Space between Intimates and Strangers*. Open University Press, Maidenhead.
- Odzakovic, E., Kullberg, A., Hellström, I., Clark, A., Campbell, S., Manji, K., Rummery, K., Keady, J., Ward, R., 2019. 'It's Our Pleasure, We Count Cars Here': an Exploration of the 'neighbourhood-Based Connections' for People Living Alone with Dementia. *Ageing and Society* <https://doi.org/10.1017/S0144686X19001259>.
- Oswald, F., Jopp, D., Rott, C., Wahl, H.W., 2010. Is aging in place a resource for or risk to life satisfaction? *Gerontol.* 51 (2), 238–250.
- Perren, K., Arber, S., Davidson, K., 2004. Neighbouring in later life: the influence of socio-economic resources, gender and household composition on neighbourly relationships. *Sociology* 38 (5), 965–984.
- Pink, S., 2009. *Doing Sensory Ethnography*, first ed. Sage, London.
- Poortinga, W., 2012. Community resilience and health: the role of bonding, bridging, and linking aspects of social capital. *Health Place* 18, 286–295.
- Risser, R., Lexell, E.M., Bell, D., Iwarsson, S., Stahl, A., 2015. Use of local public transport by people with cognitive impairments – a literature review. *Transport. Res. Part F* 29, 83–97.
- Rowles, G., 1978. *Prisoners of Space? Exploring the Geographical Experience of Older People*. Westview Press, Boulder, CO.
- Shakespeare, T., Zeilig, H., Mittler, P., 2017. Rights in mind: thinking differently about dementia and disability. *Dementia* 18 (3), 1075–1088.
- Thomas, C., Milligan, C., 2018. Dementia, disability rights and disablism, understanding the social position of people living with dementia. *Disabil. Soc.* 33 (1), 115–131.
- Vernooij-Dassen, M., Jeon, YH., 2016. Social health and dementia: the power of human capabilities. *Int. Psychog.* 28 (5), 701–703. <https://doi.org/10.1017/S1041610216000260>.
- Vernooij-Dassen, M., Moniz-Cook, E., Jeon, Y., 2018. Social health in dementia care: harnessing an applied research agenda. *Int. Psychogeriatr.* 30 (6), 775–778. <https://doi.org/10.1017/S1041610217002769>.
- de Vugt, M., Dröes, R., 2017. Social health in dementia. Towards a positive dementia discourse. *Ageing and Ment. Health* 21 (1), 1–3.
- Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., Rummery, K., Keady, J., 2018. The lived neighbourhood: understanding how people with dementia engage with their local environment. *Int. Psychogeriatr.* 30 (6), 867–880.
- Wiersma, E., Denton, A., 2016. From social network to safety net: dementia-friendly communities in rural northern Ontario. *Dementia* 15 (1), 51–68.
- Wahl, H.W., Weisman, G.D., 2003. Environmental gerontology at the beginning of the new millennium: reflections on its historical, empirical, and theoretical development. *Gerontol.* 43 (5), 616–627.
- Who, 2017. *Global Action Plan on the Public Health Response to Dementia 2017–2025*. World Health Organization, Geneva Available at: <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=BA1724B44C90C7CCC6D2461EEE325249?sequence=1>.
- Wiles, J., Allen, R., Palmer, A., Hayman, K., Keeling, S., Kerse, N., 2009. Older people and their social spaces: a study of well-being and attachment to place in Aotearoa New Zealand. *Soc. Sci. Med.* 68, 664–671.
- Wiles, J., Lieblich, A., Guberman, N., Reeve, J., Allen, R., 2011. The meaning of ageing in place to older people. *Gerontol.* 52 (3), pp357–366.
- Ziersch, A., Baum, F., MacDougall, C., Putland, C., 2005. Neighbourhood life and social capital: the implications for health. *Soc. Sci. Med.* 60, 71–86.