

**What does ‘access’ mean to people with dementia? An initial analysis
based on empirical data from walking and sit-down interviews.**

**Thematic Panel 2 – Age (ing in the) Friendly City: Global
guidelines/Diverse Realities**

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Introduction

A common thread running through the age-friendly, dementia friendly and disability studies debate is access. Access can be defined as the ‘ability to derive benefit from things’ (Ribot & Peluso, 2009); such as outside spaces, public buildings, transportation, information, knowledge, resources, and opportunities for communication and purposeful activities. An age-friendly city is expected to be accessible and inclusive of older people with varying needs and capacities, and terms such as, ‘easy access’ and ‘accessible’ are routinely used in policy debates and research about ‘dementia inclusive’ environments. In addition, access has been a long-standing theme in disability studies, where considerable attention is paid to the built environment (Imrie & Kumar, 1998) and access to education (see, for example, Nind & Seale, 2009). Given that access is such a priority in public policy, it is surprising that so little is known about what it actually means to people, particularly those with a dementia, for whom the challenges may be different from, or additional to those facing older people and persons with a physical or intellectual disability. Moreover, as the convenors of this thematic panel point out, ageing and disability policies are typically unaligned and so understandings of access are likely to vary between groups.

Accordingly, in this brief paper I seek to advance understanding of access from the perspective of people with dementia and in the context of disability studies. Dementia is a major cause of disability among senior citizens throughout the world. It is a neurological condition, which progressively and profoundly alters a person’s capacity to remember, communicate and process sensory stimuli. Persons with dementia can find it challenging to derive benefit from the everyday things that most of us take for granted, including, for example, going out and meeting friends. This is because such situations can be anxiety provoking or others may lack understanding about the nature of the impairment and/or become overly paternalistic and controlling. For example, a lack of signage and noisiness of outside spaces can deter some people from dementia from venturing outdoors (Houston, 2016); and research suggests that men can become over protective when their wives develop dementia (Boyle, 2014). Thus, for people with dementia, access is likely to be situational and a gendered process involving material challenges and power relations.

Drawing on empirical data collected for a completed study that aimed to examine the use and effectiveness of location technologies for safe walking for people with dementia, this paper examines and develops our understanding of access to people with dementia. Data were collected using a novel methodology - walking interviews with 15 people with dementia followed by a sit-down interview that included a nominated family member. Using video data, photographs, and interview text, I examine what accessibility meant to participants, all of whom were using some form of location technology. Some of the rudimentary challenges that participants faced when attempting to access places and activities that pre-dementia they would not have had trouble doing, are highlighted. The presentation concludes by arguing for greater consideration of impairment effects when theorising access and implementing age-friendly policies. In addition, it is suggested that the optimum way of learning about the realities of access for anyone is by 'walking' with that person in their local neighbourhood.

Research background

The research literature on access in relation to people with dementia is limited and focuses on access to care services. Several studies have highlighted the challenges people face trying to gain access to support and information following a diagnosis of dementia (see, for example, Beattie, Daker-White, Gilliard, & Means, 2005 and Goeman, King, & Koch, 2016). Other work draws attention to the lack of access to hospice and rehabilitation services for people with dementia; one researcher has suggested that people with dementia may unfairly lack access to surgical services due to their dementia (Graham, 2004). While this work is clearly important, care is not the only access issue for people with dementia. Persons with dementia may well want, and are entitled to access other things in life, including for example, outside spaces, restaurants and nature.

Walking outdoors and 'getting out and about' is a common and valued activity for people with dementia across the globe (McCabe and Innes, 2013). Evidence suggests that walking outdoors is beneficial for people with dementia, as it can engender a sense of self-worth within individuals (Olsson, Lampic, Skovdahl, & Engström, 2013) and help to extend the period of good quality life for families (Duggan, Blackman, Martyr,

& Van Schaik, 2008). Currently, there is a global policy quest for ‘dementia-friendly’ communities, these are places where people with dementia and their family carers feel supported to engage in community life (Mitchell, 2012). While research and policy have highlighted the importance of people with dementia getting outdoors and being in public, there is a lack of understanding about what accessibility means in this context.

The research study

The study¹ on which this article is based examined the usage and effectiveness of location technologies from the perspectives of people with dementia, family carers and the police. Data collection consisted of twenty-seven ‘go-along’ walking interviews with 15 people with dementia. Walking interviews are a hybrid of interviewing and participant observation, with the researcher walking with the informant, as they go about their everyday routines and asking them questions along the way (Kusenbach, 2003). In this study, participants were asked questions about what they liked about their neighborhood and whether they ever experienced any problems getting around. The method was selected because it is suited to research involving people with dementia, as it allows for ‘rapport-building’ and participants can find it easier to verbalize their thoughts and feelings when ‘in place’ (Carpiano, 2009). We certainly learnt a lot about the challenges people faced, when we were walking alongside them and showing an interest in their life.

After each walking interview, the researcher completed an observation form that the research team designed based on the themes identified by ethnographer Kusenbach; the form involved a series of questions about perception, spatial practices, biographies, characteristics of the physical environment and how people navigated the walk (Kusenbach, 2003). These field notes were stored and coded as part of the data set. Walking interviews were followed by 15 sit-down qualitative interviews with people with dementia (n= 14) and their nominated family member (n= 14). These included 13 spouses/partners and one niece. One person with dementia was unable to nominate a

¹ For more details about the study, see Bartlett and Brannelly (2019) *On Being Outdoors: How people with dementia experience and deal with vulnerability. Social Science and Medicine*. Published on line, 25.05.19. Ethical approval was gained from the University of Southampton, (ERGO 18348, March 2016) and the NHS and Social Care ethics process (IRAS 188932, April 2016).

person. One wife of a person with dementia was interviewed independently. Data collection started in November 2016 and was completed by April 2017. The research was conducted in the south of England and covered urban, semi-urban, and rural areas. Analysis was done through a systematic process of immersion, organising, coding and interrogating the data, and identifying salient themes and concepts using NVivo 11. A thematic coding framework was created, using abductive analysis techniques; an approach to analysis ‘aimed at theory construction’ (Timmermans & Tavory, 2012: 169). The intention was to build an explanation about ‘safer walking’ and using technology, from the perspective of people living with dementia. Codes were created from the teams’ disciplinary perspectives, as well as from scrutinising textual data and field notes. Two broad themes were identified and are presented in this paper: accessing location technologies and technical support, and accessing ordinary places.

Accessing location technologies and technical support.

Even though many people now have a GPS-enabled phone, using a location technology device provided by a telehealth care service brings additional benefits, notably someone to call when there is a problem. Most participants in this study had an Oysta Pearl, a GPS location device with an SOS alarm and falls alarm that also functions as a mobile phone and is connected to a call centre. During the sit-down interviews, participants were asked about their experiences of trying to access such a device. One family member, who had been using a mobile phone, contacted their dementia adviser to see if they could get an Oysta Pearl, but were refused as the dementia adviser said it “was not appropriate for a person with dementia”. After the initial refusal, it was unclear to them who else could be approached for access to a device. Another couple in the study had to wait over four-months for their device:

Fiona: Nothing. We were put on a listing, and they were going to send some, er, administrative, umm, paperwork through, to put us on. And nothing.

In both instances, other people had the power over access. For those who did receive the GPS device, important information was not always explained properly, and so people had to work things out for themselves. For example, one family member commented about the costs; they were expecting to pay £4 per week for the device, but

when the person got the contract they were requested to pay for twelve months up front, which was not explained beforehand. Another family member used the mobile phone to contact her husband, but when they received their phone bills, they noted calls to the number exceeded 50p per minute and they had run up substantial phone bills. They were unaware that the number would be so expensive to call.

Other family members described the initial set-up as too fast, with little information. They thought the people who set the device up assumed they had knowledge that they did not have. They relied on the instruction booklet for further information. For example, Tom and Ali wanted more information to be able to know how to use the device better. Ali wanted more time to help with set up.

Ali: Probably, but the chap that actually brought it and showed us, there was not enough time for me to digest what he's telling me, and I've tried to look through the instructions but when you are suffering with anxiety [that's hard].

Finally, some of the functions proved confusing or difficult to use for people with dementia, in particular geo-fencing – a virtual geographic boundary, enabling software to trigger a response when a mobile device enters or leaves a particular area. For example, during the walking interview with Shaun, the alarm sounded on his device because we had walked outside of his defined 'safe zone'. Initially, Shaun did not hear the alarm (he was hard of hearing) but when he did, he pulled a face as if to say 'what's the point of that? The episode highlighted how other people (e.g. family members and telehealth care workers) often define the boundaries of access rather than the person with dementia themselves. Other people with dementia had difficulty using the GPS devices to make calls, to answer calls and to use the SOS button. Michael was unsure of the functions of the buttons on the Oysta Pearl, and was practicing to get them right. Tom was unsure what the SOS button was for, as the following exchange shows:

I: And what is that big blue button then in the middle? What does that do?

Tom: I don't know what that is actually. I've not got round to sort of like fathoming that one out.

Three of the men in the study commented that the devices were too small for their fingers. Some participants described the volume on the Oysta Pearl as low, and had difficulty hearing when using the phone function. Participants' sensory needs were not always considered when introducing the technology, which again shows how the effects of impairment can be overlooked.

Accessing ordinary places

We asked participants why they wanted to go out; the reasons people gave are listed in table one. People gave the same reasons that anyone might give for going out, such as going to the shops or hairdressers, walking the dog, and meeting friends for coffee. Only one person mentioned anything related to care or illness, and that was Iain who had to go out for a hospital appointment. Clearly, accessing ordinary places is as important to people with dementia, as it is to anyone.

<i>Participant</i>	<i>Reasons for getting out and about</i>
Tom	Shopping/getting errands, fishing, car boot sales, pub with friends, get air, days out
Penelope	Blackberry picking, to feed the ducks, visit church, lunches, helping neighbours, coffee mornings
Sadie	Shopping, walk the dog, hairdressers, visit friends, out for meals, holidays
Rose	Walking the dog, shopping, meals out
William	Walking for fitness, shopping, days out, sports events
Frank	Volunteer, shopping, coffees out, meals out, gym, cycling
Iain	Shopping for groceries, days out, hospital appointments.
Nicholas	Walks the dog.
Joe	Walks the dog, shopping for errands, meals out. Likes to take the dog out, get a bit of space, get out of wife's way.
Michael	Shopping for errands, get out of the house, drinks and meals out, days out
Shaun	Daily long walk for fitness, coffees and meals out
Bernard	Post letters

Melanie	Sits out on the coast, shopping for errands.
Eddie	Shops for errands, occasional walk for air
Anne	Getting air, long walks, picnics, hairdressers

Table 1 - Reasons stated by participants for getting out and about

What we discovered is that participants faced an array of challenges when attempting to access ordinary places and activities that pre-dementia they would not have had trouble doing, such as opening gates and going out. Furthermore, it became apparent during the walking interviews that many of these challenges were due to impairment effects. For example, in the following video sequence, we can see how easy it is for Tom, a keen angler, to walk along a path until he reaches a physical barrier – a lock on a gate. Tom attempts to unlock the gate, but the process involves manual dexterity and cognitive processing, both of which are challenging for him due to the dementia. Nevertheless, he remains calm and tries for three or four minutes to unlock the gate.

Sometimes gaining physical access to a place is not the problem, it is that the person is not meant to be there. For example, Penelope reported being caught innocently trespassing whilst she was out blackberry picking because she had not realised she was on private grounds. She said: *‘a little boy rushed over. They were playing football, and he said what are you doing, and I said picking blackberries. And I didn’t realise it was a private school’*. During one sit down interview we heard how a participant once got on the correct bus but it was travelling in the wrong direction; fortunately his wife worked it out from looking at his tracker on their home computer, and was able to locate him. Similarly, during the sit-down interview with Shaun we heard how he used to get on the bus and travel for miles. Sometimes the police had to pick him up. In all these

cases, the access issue is a cognitive rather than physical one, which others may not understand.

Dementia is a hidden disability when the effects of the condition are not visible to others. As cognitive processes are impaired, it can be difficult for others to understand why someone might have a problem doing ordinary things. For example, during their sit-down interview, Michael and Julie spoke about how they like to go out to eat but this had become problematic because Michael was no longer able to choose what to eat. As his wife said: *He can't make a decision if we go out and eat.* To which Michael responded: *Well I find it hard to make a decision.* Even spouses can lack understanding of impairment effects.

In conclusion, for access and accessibility to have meaning in the context of persons with dementia, account needs to be taken of cognition and cognitive differences.

Currently, most access work and age/dementia-friendly initiatives focus on the physical rather than mental demands of a given environment. Yet, for people with a dementia, access is primarily a cognitive process and challenge, as opposed to a physical one.

Unfortunately, the effects of impairment are such that other people do not see or understand this; hence, city-level priorities and strategies do not address them. But as this brief paper has shown, it is important that they do. Finally, we would suggest that the optimum way of learning about the realities of access for anyone is by 'walking' with that person in their local neighbourhood.

