

Using walking interviews to enhance research relations with people with dementia: methodological insights from an empirical study conducted in England.

Ethics and Social Welfare

Practice section

Authors

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Using Global Positioning Systems for Safer Walking.

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Abstract

Ethical research practice requires inclusionary approaches that enable people to contribute as fully as possible. Not enough is yet known about the impacts of dementia on daily life, however, people with dementia may find inclusion in research challenging, as the 'cognitive load' required may be overwhelming. When responding is difficult, others may contribute and the voice of people with dementia may be diminished. In this paper, the method of walking interviews is reflected on following a study that examined the acceptability and usefulness of Global Positions Systems (GPS). Attention is drawn to an observation of the contributions people with dementia made whilst out walking with the researchers. When out walking, people with dementia used the environment as sensory prompts to start conversations, and these discussions shaped research data, and enabled people with dementia to raise concerns about the impacts of dementia, their futures and what they feared for themselves and their families. The challenges that people with dementia faced in negotiating everyday practices were visible. The person with dementia showed the researcher around their neighbourhood, and this significantly changed the interview dynamic and positioned people with dementia as leading the interaction.

Keywords: dementia, qualitative study, walking interviews, citizenship, participation

Word count: 4090

Background

The importance of involving people with dementia in research about the experience of dementia or possible interventions has been emphasised (World Health Organisation 2016). Methods of data collection such as interviews are sometimes not suitable as they do not accommodate individual needs or capacities of people with dementia (Keady, Hyden, Johnson and Swarbrick 2017). The pressure to recall and recount events, or cognitive load, can silence a person with a cognitive disability like dementia (see, for example Osman, Tischler and Schneider 2016). Researchers increasingly try alternative methods such as walking interviews to improve the involvement of people with dementia in research. The study used as an example in this paper, *Using Global Positioning Systems for Safer Walking*, used a combination of sit-down and walking interviews to elicit insights about the value of being able to continue to go out and about using location technologies from people living with dementia in England. The difference between the levels of participation by people with dementia in the sit-down interviews compared to the walking interviews was remarkable. The walking interviews evoked a ‘different quality of talk’ (May and Lewis, 2019 p11), from the sit-down interviews with family members. Most notably, the person was in control of the walking interview because the encounter was led by them, and they hosted the researcher in their environment. People with dementia looked forward to going out, environmental cues prompted conversations and remembered stories, and people with dementia engaged in discussions about aspects of their lives that were not revealed with family members present. This repositioning of control and an emphasis on the current concerns of the person created a more participatory approach to the research and one in which the person with dementia was at more ease while participating.

The manner in which an interview is conducted has been a long-standing methodological concern in studies that involve people with dementia (e.g. Hellström, Nolan, Nordenfelt and Lundh 2007; McKillop and Wilkinson 2004). Mostly, this work has focused on the practicalities of interviewing people with dementia, such as organising an appropriate time of day and considering the optimum setting for an in-depth interview (Cridland, Phillipson, Brennan-horley, Swaffer 2016). As is usual in research interviews, it is recommended that researchers ‘establish a rapport within the interview process’ so the encounter is experienced as a constructive one for all involved (Cridland, Phillipson, Brennan-horley, Swaffer 2016 p1781), and one recommendation is that multiple, serial interviews enable people to get to know the researcher and build trust. It is noted that the interview setting and process influence the research relationship and quality of data, and research by disability scholars indicates that it is important to consider this link, given that certain situations and

approaches can exclude people with particular communication needs (Nind 2018). This is indicative of a respectful approach to including people with dementia in research.

Two essential considerations in research are autonomy and consent, and both may be difficult to navigate when researching with people with dementia. Autonomy is understood as the ability to make independent decisions about one's life, and in order to achieve this the implications of those decisions need to be understood. Consent also involves the need for information about what the person is consenting to, and the implications of the decision to consent. For people with dementia, this may be prescient on receiving information in a way that is useful and perhaps, revisiting a decision on a number of occasions. This approach is congruent with the principles of the UK Mental Capacity Act (2005). This staged and careful practice is supported by researchers having multiple contacts with people with dementia and, where possible, family members for support.

A commitment to ensuring the inclusion of people with dementia in research is an ethical imperative, and challenge that qualitative researchers have embraced (McKeown, Clarke, Ingleton and Repper 2010). Including the views of people with dementia in research is important for not only the advancement of scholarship and policy, but also that it is the right thing to do, ensuring opportunities for participation by the person with dementia. Being able to contribute to the advancement of scientific knowledge about dementia is a chance for active citizenship – potentially, it is an ‘act of citizenship’ (Isin and Neilson 2008) – in that participation opportunities, challenge the notion that dementia means passivity and exclusion (Swaffer 2016). However, research is only inclusionary for citizens if account is taken of their capacities and circumstances. Research generally assumes that a person has ‘a perspective’, which requires a perception of oneself as an individual and the ability to represent one’s situation in words, however, this can exclude people who have difficulty expressing themselves verbally from research (Pols 2005, p203). The challenge for researchers is to enable the involvement of people with dementia in a way that encourages participation and enables contributions with thought and consideration of the abilities of the person.

Interviewing, despite its difficulties, remains a favoured method of data collection, as it is across the health and social sciences (Edwards and Holland 2013). The popularity of the method is clearly attested by a recent meta-synthesis of how people with dementia cope, in which individual interviews constituted the main data source for 64 of the 74 articles reviewed (Bjørkløf, Helvik, Ibsen, Telenius, Grov and Eriksen, 2019 p3). Typically, interview-based studies involving people with dementia take place indoors; even studies concerned with the person’s neighbourhood (Smith, Gee, Sharrock and Croucher 2016) and experiences of outdoor life (Olsson, Lampic, Skovdahl and Engström, 2013) use sit-down interviews at home. This standard approach to data generation relies

solely on talking – something that a person with dementia may find challenging to do - and reveals very little about what the person may or may not accomplish outside the home.

Walking interviews

In recent years, health and social care researchers have begun to realise that ‘mobile data generation’ outdoors can help to ‘subvert the traditional authority/power relations between interviewer and interviewee’ (Brown and Durrheim 2009, p926), evidenced by the increasing number of studies using the approach (Clark and Emmel n.d.). Walking interviews have been part of anthropological research for many years. In ethnographic studies, researchers have walked alongside members of communities to make sense of everyday practices (Clark and Emmel n.d.). More recently, walking interviews have been used in the social sciences to access everyday practices and make sense of them, with researchers and research participants walking together, often in the participant's neighbourhood. A unique feature of walking interviews is that the interview is situated in the environment, where the conversation is contingent on the surrounding visual and aural distractions rather than on researcher questions (Brown and Durrheim 2009 p921). These are also sensory stimulations that form environmental cues for people with dementia who use them to recall aspects of daily life or respond in body. As Pols (2005) points out, everyone has a practice, even though not everyone can make verbal representations of it - exploring what people do, rather than say, can make visible what they appreciate and what they would rather avoid. This approach allows for the repositioning of the person with dementia from having an impairment and not knowing how to answer, to having localised and situated knowledge that can be shared. Here, it is argued that greater use of walking interviews may elicit the private thoughts and practices of people with dementia.

Walking interviews are a hybrid of interviewing and participant observation, whereby the researcher walks with the informant as they go about their everyday routines and asking them questions along the way (Kusenbach 2003; Garcia, Eisenberg, Frerich, Lechner and Lust, 2012). The method is deployed by researchers to contextualize data (Garcia, Eisenberg, Frerich, Lechner and Lust, 2012) and to capture the embodied nature of knowledge in a way that cannot be gained from a seated interview (Doughty, 2013). Recently, walking interviews have been used in studies involving people with dementia to collect data about their neighbourhood (Ward, Clark, Campbell, Graham, Kullberg, Manji, et al 2018; Odzakovic, Kullberg, Hellström, Clark, Campbell and Manji, et al 2019). In studies where people with dementia have gone out walking with the researcher, the activity is described as

a 'confirmation of the self' (Olsson, Engström, Skovdahl, Lampic 2012, p793) and the 'sustained interaction' can help people to 'open up' even if their 'initial responses are limited' (Capstick 2011, p146). Additionally, researchers have found that exploring the neighbourhood together can boosts a person's confidence (Doughty, 2013), so that research is experienced as a positive, sustaining activity.

This paper presents some observations from using the method of walking interviews where a person with dementia was accompanied for a walk as an inclusive, active and non-threatening way of getting to know a person and the environment in which they live. When researching with people with dementia, the relationship 'begins with valuing the experience of being present with another human being, trying to understand that person's experience and to know the uniqueness of the person' (Molony, Kolanowski, Van Haitsma and Rooney 2018 p33). Walking around one's neighbourhood is an important part of everyday life and a key component of physical and mental health (Olsson, Engström, Asenlöf, Skovdahl and Lampic, 2014). However, people with dementia may 'feel out of place in outside space, with some curtailing activities and others being guided by the physical and social environments which they inhabit' (Brittain, Corner, Robinson, Bond, 2010 p283) . Indeed, in this study we witnessed how people with dementia struggled to deal with the vulnerabilities of dementia in an outside setting (Bartlett and Brannelly 2019). This provided new knowledge of the challenges faced by people with dementia when navigating everyday practices, providing a fuller picture of an individual's life, including when outdoors.

The research

A three-phase qualitative participative inquiry examined the effectiveness and acceptability of GPS location technologies from the perspectives of people with dementia, family carers and the police. An advisory group of people with dementia, family carers, police, practitioners and advocates contributed to the research. Phase one included focus groups with the police ($n=20$) and interviews at home with people with dementia($n=16$) and family members($n=16$). Phase two included two walking interviews with 15 people with dementia ($n=27$) and an interview with people with dementia and family members at home ($n=15$). In phase three, project advisory group members (people with dementia, family carers, practitioners and police) and research participants joined residential workshops in a rural location to develop analysis and prioritise findings.

Participants were living at home, either alone or with family, and were using a tracking technology such as a mobile phone app, or a specifically designed technology supported through local authority funding. People with dementia were aged between 55 and 85 years. 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. One concern about the walking interview method was that the walks were all scheduled over winter, however, all the participants wanted to go out walking, and despite the cold, rain and frost there was a rare postponement (two cancellations in minus temperatures). The length of walks varied. The shortest walk was one third of a mile that lasted 7 minutes and longer walks were for three miles and lasted for an hour. Mostly, the walks were in urban areas, or small village settings. One of the walks was in a rural environment, on country lanes surrounded by fields and occasional houses. Two walks were taken along the coast. Participants were adept at navigating their usual environments including very busy dual carriageway roads that were very noisy, or quiet country lanes with fast traffic. They negotiated these easily as they were accustomed to doing so. If a person with dementia was noted to lack road safety while out with the researcher, there was a pre-walk agreement that this would be raised for discussion on return. Although this did not occur, the walk carried a risk of exposure for the person with dementia.

Ethical approval was gained from the University of Southampton (ERGO 18348, March 2016), and the Health Research Authority (IRAS 188932, April 2016). Ethical considerations concerned consent by people with dementia who may lack capacity. Mental Capacity Act (2007) principles were applied to the research process, including that the person with dementia was assumed to be able to consent and accessible information was made available (developed with the advisory group). If it was apparent that the person was unable to retain the information, they were asked if it was acceptable that their family member agreed on their behalf. Attention was paid to how the person responded during the research process and participation was abandoned if any distress was shown (one person was withdrawn from the research as they were anxious about participation and were unable to consent).

NVivo 11 was used to manage all forms of data including the interview transcripts and photographs. Analysis was through an interdisciplinary systematic process of immersion, organising, coding and interrogating the data, and identifying salient themes and concepts. A thematic coding framework was created, using abductive analysis techniques; an approach to analysis 'aimed at theory construction' (Timmermans and Tavory 2012 p169). The intention was to build an explanation about 'safer walking' and using technology, from the perspective of people living with dementia. In line with an abductive approach, there was a brief coding-window when new inductive codes were developed - these were biography, health and dementia. All codes were reduced using summaries that held the feel of the data while decreasing the volume.

The study set out to examine the acceptability and effectiveness of GPS to promote safer walking for people with dementia and found that that GPS was welcomed as a helpful adjustment to aid location by people with dementia, their family carers and the police. Early adoption and advance planning for using GPS was prioritised by people with dementia, who emphasised the need for consent to use location technologies.

The walking interviews generated observation field notes which included a series of questions about perception, spatial practices, biographies, characteristics of the physical environment and how people navigated the walk, adapted from Kusenbach (2003). These field notes were stored and coded with the rest of the data. Video capture was used to record the environment and the conversation whilst out walking, rather than focus on the participant to provide a view of the walking environments, which varied from quiet country lanes to busy major road intersections. The following extracts show how the walking interviews enabled a space for expression and control of the situation thereby reaffirming ability and confidence. All names are pseudonyms.

New insights while out walking

The researchers did not know the areas where the walking interviews took place, which positioned the person with dementia as the guide, who navigated and pointed out aspects of interest. People with dementia led the way:

Researcher: So where shall we go now Anne?
Anne: Well we can go back that way.
Researcher: Yeah.
Anne: Or we can get back this way, so that's alright. So, whichever. It doesn't matter which way we go does it?
Researcher: No.

Participants also explained the planned route and explained orientation:

Frank: We've got to re-trace our route.
Researcher: Right. Well if you asked me to get back to your house from here I wouldn't have a clue. So, I'm glad you're here.

There were examples of orientating the researcher:

Researcher: Yeah. Are we up that way?
Penelope: Yes.
Researcher: Ah, ah, I've found some bearings!

People with dementia were invited to lead and show the way:

Joe: Where are you going?

Researcher: I'm following you.

Joe: Oh!

Researcher: So, wherever you like?

Joe: Oh, that's alright.

One of the participants slowed the researcher's walking pace:

Iain: You are like a greyhound.

Researcher: No! I've got a terrible tendency to just put my head down and get walking.

Iain: Sorry. Oh dear, oh dear.

Researcher: Sorry about that.

Iain: Ah, don't worry. No, honestly, you know what, I'm eighty something.

Researcher: I know. [Laughs].

Iain: What do you think I am, I am!

A participant who had expressive dysphasia was unable to participate in the sit-down interview.

During the walking interview, he showed the researcher the way to the post box to post a letter, which involved navigating through a housing estate, whistling and singing all the way. In this situation, the buildings and streets were so similar that it was necessary to have committed the route to memory rather than look for obvious landmarks.

Data were coded for 'interactions outdoors' and this showed that participants with dementia valued social encounters. For example, whilst conducting the walking interview with William he spoke to two long-time neighbours about family and current news. People met neighbours and friends and chatted about mutual friends and families, or general chitchat about the weather or dogs out walking too. These conversations prompted explanations to the researcher about social connections and relationships over the years. People with dementia recounted past adventures and current activities. For example, Iain told us how much he liked walking to his local supermarket; partly because it involved walking past a house where '*there's one chap*' doing his garden. He said: '*I have a little chat with him...and it's really nice*'. Later in the interview, he emphasised how much he enjoyed bumping into people and having a chat when he was outdoors. He said: '*I like people*' and '*I talk to everybody*'.

Naturalistic questioning about who people were that we met coincidentally when out led to other discussions about the impact of dementia. People with dementia explained the impact of dementia

differently when they were out walking. For example, Patricia disputed having memory loss with her daughter present but did not when alone with the researcher.

Researcher: Do you bump into people that you might know?

Patricia: Oh yeah. Well some people say hello Patricia how are you, you know, or hello, and I think who the hell is that. Memory loss.

Researcher: Right, okay.

Patricia: I have got memory loss.

Penelope had always volunteered to help others and wanted to continue this when out walking on her own. Helping others was a valued part of her self -identity, and something she was keen to continue to do.

Penelope: And meet up to one or two elderly people, well who sit on the seats in the park and chat to them, you know so.

Researcher: Yeah.

Penelope: So that they've got somebody apart from the ducks, to talk to!

Being outdoors provided an opportunity for the person to speak candidly with the researcher. Many participants asked the researcher for an appraisal of their dementia. For example, during her walk, Sadie asked the researcher:

Sadie: Well how do you think I seem, after these few weeks.

Researcher: I think you seem great.

Sadie: Thank you. That's the main thing then. Well that's quite, you know just to keep yourself.

Researcher: How do you feel like you're getting on?

Sadie: Fine.

One participant moved into a new area. Part of the conversation about moving to a new area was questioning her ability to be able to navigate, and this had caused the person with dementia some concern so she was occupied with demonstrating her cognitive abilities by working to commit local roads to memory, and show that she was able to establish a walking routine.

Penelope: And that's Peak's Avenue.

Researcher: Right.

Penelope: See, I have remembered another road.

Completing everyday tasks exposed functional difficulties that the people with dementia in this study faced. Posting Christmas cards presented quite a challenge for one person, who needed to lay out the cards on the ground at the doorstep to decipher which card was to be posted at the address. With five cards to post, the first three were most challenging. William was aware that this was unusual behaviour and pondered what his friends thought about him having to do this on the doorstep. Coordination difficulties were experienced with 'contactless' debit cards, shopping bags, shopping lists, locks and gates. Many of the people with dementia described anxiety as the overwhelming feeling when faced with the challenges that dementia had brought.

People with dementia shared how they viewed their dementia and described its impacts. Becoming a burden was a common theme whereby people with dementia were acutely aware of the changing relationship with their partner and were fearful about the future. These conversations were not initiated by researchers but were sometimes prompted by environmental cues. On passing a care home, one participant commented about how she had supported a friend with dementia who had lived there and considered the possibility of living there herself one day. The participants tended to manage risk by sticking to known paths, stopping and checking location and direction to return home safely, or staying indoors. When out alone they described asking for help from passers-by and being returned home by people that had asked for help, particularly in village settings. Taking the opportunity to go out with the person with dementia enabled multiple levels of assessment and understanding of the impact of the dementia on the person from their perspective and was welcomed by the person with dementia and their family member.

Discussion and concluding comments

This research study used walking interviews with people with dementia, and researchers reflected on how different the data was that was generated during the walking interviews when compared to sit down interviews where people with dementia tended to be quieter, or more deficit focussed and where family carers tended to dominate. The process of walking and talking was amiable and active and enabled the person with dementia to lead the way thereby taking a strengths-based approach. Other researchers who have used this approach with people with dementia have also found that it importantly provides a way for people with dementia to 'explain who they have been and still are' (Odzakovic, Kullberg, Hellström, Clark, Campbell, Manji, et al 2019 p7) maintaining a sense of self and identity easily lost by less inclusive approaches. Given these findings, the same approach has the potential to be used in community-related studies.

This study corroborates the view that mobility is an integral aspect of wellbeing. Yet, walking for people with dementia is regularly associated with negative risk, or questioned for its necessity. The

need to walk by people with dementia has conventionally been disparaged, referred to as 'wandering', suggesting people with dementia walk without purpose (Robinson, Hutchings, Corner, Finch, Hughes, Brittain, and Bond, 2007). This view is consistent with a functional approach to walking where walking is seen as an act of transport from A to B, with less emphasis on incidental social aspects and the value of being in one's community. The 'new mobilities' paradigm emerging in social geography views movement as social and networked, rather than as a linear A to B movement (Sheller M, Urry 2006; Germann Molz, 2006) Movement is viewed as central to humans' everyday experiences and social relations, to understand and describe those experiences in creating and shaping social relations (Burnett, Lucas 2010).

This research study was a small study that examined practices related to GPS and dementia in one county in the south of England. There was little diversity in ethnicity or sexuality of the participant group. The sample was small, and the findings are not generalisable. The study does explore in depth perspectives of the participants and offers insights into their experiences of living with dementia and using GPS technologies.

Walking interviews offer an alternative way of getting to know a person with dementia and their support networks connected to home. Walking with someone is an opportunity to understand everyday practices and the significance they hold in everyday experiences. People with dementia expressed connection to place, both past and present in a way that expressed and restored identity. This research study shows that such an approach is suitable and effective for qualitative research highlighting the value of walking and talking with a person with dementia in their local area, to build rapport and equitable relations. Given how easy it is for someone with dementia to be positioned as 'incapable' and excluded from conversations and the outside world (see for example Swaffer, 2016) this seems reason enough for researchers to adapt go-along walking interviews; as they create opportunities for acts of citizenship with people with dementia.

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