Abstract

Vulnerability is a problematic label routinely applied to people with dementia, yet their situated experiences of vulnerability have not been prioritised or documented. Drawing on empirical data collected using a novel methodology - walking interviews with 15 people with dementia living in Southern England, followed by a sit-down interview that included a nominated family member - this paper advances understanding of how vulnerability is experienced and dealt with by people with dementia when outdoors, and at times shared with family carers. Data were analysed using abductive techniques; a thematic coding framework was created from the dataset, in addition to the application of critical theories of vulnerability and disability. We found that vulnerability is characterised by a sense of 'ontological vulnerability' for the person diagnosed with the condition - that is, an awareness of failing knowledge about oneself or the 'rules' of outdoor life, which individuals experienced emotionally and dealt with civically. People with dementia attempted to manage risks and anxieties, often doing this independently so as not to burden family members. These findings highlight how people with dementia experience and deal with vulnerability when outdoors, which others need to acknowledge and support to enable people with dementia and their families to work though these challenges, in a family-orientated way when risk planning.

Key words: UK, civic life; dementia; disability; lived experience; outdoors; vulnerability

1. Introduction

There is a consensus in the research, policy and practice literature that men and women with dementia are a 'vulnerable group', but what does vulnerability mean in this context? Dementia is a disability characterised by severe and progressive neurological changes, as well as stigma and discrimination. Hence, the label 'vulnerable' is routinely applied to people with dementia (e.g. Department of Health, 2009, World Health Organisation, 2012). However, there are significant gaps in understanding about the subjective nature of that vulnerability and the factors shaping it. While research has highlighted the importance of taking the perspective of the person with dementia, we still know very little about how people with this condition think and feel about their vulnerabilities, particularly when they go outdoors. This is a problem, because without this knowledge, it is difficult to support people with dementia to lead less vulnerable lives.

This paper aims to advance understanding of dementia as an impairment and disability, by examining the outdoor lives of men and women with dementia living at home in the context of sociological discourses on vulnerability, disability, and citizenship. In particular, we analyse how this group of citizens experience the outside world and deal with the challenges they face. The empirical data come from a qualitative study on people's use of location 'tracking' technologies, in which vulnerabilities associated with going out was identified as a key theme identified through abductive analysis of the data, and an unexpected thread running through the accounts reported by people with dementia. We argue that vulnerability is characterised by a sense of 'ontological vulnerability' for the person diagnosed with the condition - that is, an awareness of failing knowledge about oneself or the 'rules' of outdoor life, which is felt emotionally and dealt with civically – that is, within the public sphere. Furthermore, we argue that vulnerability is shared within the family; it is not just the person

with dementia who is at risk. Thus, the paper concludes by recommending that practitioners acknowledge and support people's vulnerability outdoors in a family-orientated way when risk planning.

2. Vulnerability and Dementia

Vulnerability is a problematic label applied to people with dementia. It comes from the Latin word *vulnus* (wound) and is taken to mean fragility and helplessness; but this is too narrow a view (Calhoun et al., 2014). As Wiles (2011) explains: 'vulnerability may be conceptualised as fragility and (or) weakness, but it could also be conceptualised as openness, susceptibility, and receptiveness' (p. 579). Consider, for example, how stoic a person with advanced dementia has to become in the wake of others' lack of compassion (McNess, 2017). In addition, many people with early dementia are willing to speak in public about their diagnosis and the problems they face (Bartlett, 2012). Thus, the idea of vulnerability as necessarily denoting weakness needs scrutiny. In particular, it needs analysis in the context of outdoor life, as this is when people with dementia are considered vulnerable, but expected to be independent. Our research findings suggest that people with dementia attempt independence at considerable personal challenge.

Social science literature on the link between vulnerability, disability and citizenship, is not extensive, and to date, there has been no theorisation of the distinct experiences of people with dementia. Most often in discussions of vulnerability, people with dementia are an exemplar, rather than focal point. For example, Turner (2003) who has written extensively about how 'human beings are ontologically frail and their natural environment, precarious' (p.276) refers to people with dementia but does not examine this situation in any detail. In complementary work by feminist scholars, attention is paid to how 'vulnerability' is used as a

fixed label in relation to particular subpopulations (Luna, 2009: 121). Furthermore, questions are raised about how certain forms of vulnerability are contingent upon social factors such as disability and gender (Calhoun et al., 2014). However, the nature of vulnerability associated with the experience of dementia is not covered. There has been some work in disability studies on the link between vulnerability and citizenship, which advocates for more research on the 'new and continuing forms of vulnerability' as experienced by people with disabilities (Beckett, 2006: 2). Thus, a focus on vulnerability in relation to men and women with dementia would help to advance vulnerability and citizenship studies.

Understanding vulnerability from the perspective of citizens with dementia is key to achieving social justice, as it promotes the view that 'an adult with dementia remains a member of the community and is entitled to be cared for compassionately' (Behuniak, 2010: 238). In recent years, there has been a renewed emphasis on recognising and upholding the human rights of people with dementia (Cahill, 2018). Importantly, scholars are arguing for increased recognition of the shared vulnerabilities and responsibilities of care associated with dementia (Brannelly, 2016), so that 'acceptable responses that give scope for agency (or some variant thereof) and the maintenance of human dignity' might be developed (Grenier, Lloyd, & Phillipson, 2017: 236). Whilst this work is fresh and vital, much of it is theoretical and lacks an empirical basis.

Recent studies of life outdoors provide a useful empirical basis for examining the link between vulnerability, dementia and citizenship. This work focuses on how the dementia affects a person's relationship with themselves, other people, and the area in which they live. For example, scholars report how people with dementia experience their local

neighbourhoods as places of opportunity and challenge (Ward et al., 2017). Others have found that people with dementia can 'feel out of place in outside space' (Brittain, Corner, Robinson, & Bond, 2010: 283). Work has shown that people with dementia are vulnerable and at risk in surroundings that are experienced as unfamiliar and confusing (Sandberg, Rosenberg, Sandman, & Borell, 2015). Such risks include feeling inadequate and dependent on others for support and guidance (Olsson, Lampic, Skovdahl, & Engström, 2013). Critically, the person with dementia may be unaware of the risks they face when they are outside (Smebye, Kirkevold, & Engedal, 2015). This work helps to explain why outdoor life can become a 'shrinking world' for people with dementia (Duggan, Blackman, Martyr, & Van Schaik, 2008), and why more research needs to focus on vulnerability, as perceived by people with dementia themselves.

In the UK, policies have constructed 'vulnerability' in terms of the need for protection. For example, in adult safeguarding policies and practice guidance, people with dementia are described as 'extremely vulnerable' due to the nature of the condition; in serious cases of abuse they become victims (Manthorpe & Martineau, 2016). Whilst it is clearly important to protect people from harm, to wield the 'vulnerability' label in an uncritical way for everyone with dementia is problematic. Not least because we know that people with dementia are aware of being treated in a paternalistic way and want control over their life (Eriksen et al., 2016).

Several empirical studies have highlighted the capacity of people with dementia to deal with the challenges they face when outside. This includes engaging in 'new and innovative types of interaction' (Beard, Knauss, & Moyer, 2009: 234); such as, connecting with shopkeepers and other key actors in the neighbourhood (Ward et al., 2017). This work is underpinned by

global policies related to 'dementia-friendly' communities – places that strive to empower, support, and include people with dementia in everyday life (World Health Organisation, 2017). Another significant area of work explores the use of Global Positioning System (GPS) 'tracking' technologies to support inclusion and independence. Overwhelmingly, this work shows that such technologies are valued by people with dementia and their families, primarily because it provides 'peace of mind' to both the carer and person with dementia (e.g. Oderud, et al, 2015, Landau, Werner, Auslander, Shoval, & Heinik, 2009). What has not been adequately elucidated in the research literature are the concerns that people with dementia might have about using such technologies, and in particular, whether or not it shapes their experiences of vulnerability, and responsibilities and practices as a citizen. A novel aspect of our work is using a critical disability lens to examine outdoor life and people's use of GPS 'tracking' technologies. As such, the paper aims to privilege the perspective of people with dementia, and advance understanding of how vulnerabilities associated with the experience of dementia impact on citizenship.

3. Research aims and methods

This participative inquiry examined the usage and effectiveness of location technologies from the perspectives of people with dementia, family carers and the police. Participative inquiry is a useful methodology for research involving vulnerable adults as it can empower people to reflect and share, take control and contribute to areas of life that concern them; participation is central to the approach (Reason, 1994). Hence, the project was designed to maximise opportunities for dialogue and to help build equitable and empathetic relationships between those involved.

A maximum variation sampling approach was used for recruitment, meaning a heterogeneous sample was deliberately sought and selected to observe commonalities and differences in experiences of using technologies for safer walking (Given, 2008). Participants were recruited via Admiral Nurses (who provide specialist dementia support to families), Memory Service Occupational Therapists, and Alzheimer Society and Mind Dementia Advisers between April and November 2016. 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). Ethical considerations in the project were concerned with the inclusion of people with dementia who may lack capacity to provide consent, but who should be given a voice through the research project, and were likely to be using the technologies to stay safe. Applying the Mental Capacity Act 2005 to the research process meant that the person with dementia was assumed to be able to consent, and accessible information was made available. If it was apparent that the person was unlikely to understand 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).

3.1 Data collection

The work consisted of two sequential phases of data collection, followed by a third co-production phase. Phase one involved focus groups with the police (n=20) and individual interviews with people with dementia (n=16) and family members (n=16). The results of these phases are not reported in this paper, so no further information is provided about them. Phase two employed go-along walking interviews with ten men and five women with dementia (n=15) who were carrying some form of technology, such as a GPS device or phone app, when they went out. When the study began, participants with dementia ranged in age

from 55 to 85. The third phase involved an overnight residency with key stakeholders including research participants – the aim of which was to share preliminary findings and co-produce key messages for policy makers.

For phase two, twenty-seven 'go-along' walking interviews were conducted with 15 people with dementia (see table 1). 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 our study, participants were asked questions about what they liked about their neighborhood and whether they ever experienced any problems finding their way 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 found that people opened up about how they were feeling and what they thought about having dementia, when we were walking alongside them and showing an interest in their life.

Two walking interviews were planned, as multiple opportunities to talk work well with people with dementia to enable multiple partial conversations. Some walks were longer than others were. The shortest walk was 0.33 miles and took 7 minutes. Longer walks were around three miles, and were close to an hour. During one walking interview, the rain got heavier so the researcher and participant returned home. One participant was unsure about the walking interview and the second walk was not arranged; two were abandoned due to poor weather. Mostly, the walks were in urban areas, or small village settings. Only one of the walks was in a completely rural environment, where the walk from the house went

straight into country lanes with fields and few buildings. This was a longer walk that ended back in a village before heading home. Two of the walks were taken along the coast and both participants commented on the wellbeing they encountered from walking there. In some areas, such as housing estates, it was difficult to get one's bearings as the buildings and streets were so similar that it would be necessary to have committed the route to memory rather than look for obvious landmarks.

Insert table 1 about here

After each walking interview, the researcher completed an observation form that TB 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 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. TB was the main data collector. RB co-facilitated one of the focus groups, and carried out the walking and sit down interviews with two participants.

3.2 Data management and analytical steps

The sit-down and walking interviews were transcribed. The main data collector (TB) prepared and imported textual data and photographic images into NVivo 11. Analysis was

done through a 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 & 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. The process began with each team member reviewing the same set of interview transcripts independently, selected for their complexity, and highlighting any key points of interest to them, which we then shared and discussed as team. After this, a coding schema was agreed by two members of the research team (RB, TB) and applied to four interview transcripts. An inter-rater reliability test was conducted within NVivo and the average for agreement was 83%. All textual data were then coded using the agreed thematic coding schema. Having coded the data, we ran queries and created visualisations of the data to explore the coded data in more detail.

4. Findings

4.1 Vulnerability within the self

Whilst talking about their experiences of being outdoors, participants with dementia reflected on how the condition affected them. The medical view of dementia prioritises cognitive decline and loss of self; however drawing on the walking interviews with Frank, Joe and William, unfathomable sensations within the self were spoken about more than cognitive decline. For example, Frank describes the experience of having dementia as 'weird', as if he knows what he is doing at the same time as not knowing what he is doing. Similarly, Joe spoke about what it was like to have Alzheimer's disease, and how he was finding it hard to

deal with. He too described the sensation as 'weird', like nothing he has experienced before. He looked quite distressed whilst talking about it. These comments show how insecure these men felt inside, whilst they were out and about. The fact that they were voiced during walking interviews (when their wives were not there) suggests an awareness of failing knowledge about oneself (i.e. ontological vulnerability), which they did not find it easy to talk about;perhaps because it made them feel, or seem to others, even more vulnerable.

Another participant, Iain, reported on how deeply the dementia affected him when he was outdoors. During his sit-down interview he recalled a time when he was out and about and admitted to not knowing anything about himself. He said: '*I didn't know who I was, who anybody was…..I didn't even know where I lived'.* The effects of dementia were such that he could no longer rely on knowing any of the fundamental facts about his life; a failing knowledge base that he was clearly aware of. Frank reported a similar sensation when he was out, although for him it was more of a 'fuzzy feeling' and sense of being disconnected. He said: *I know (the dementia) is in my brain, it's most probably not in my head, umm so you know it's, yeah it's strange at times.* Other participants sought to pinpoint the bodily source of their vulnerability. For example, William felt that the dementia was situated in his brain, and he wanted rid of it; when asked if there anything else he wanted to say at the end of his sit-down interview, he said: *'Just get (the dementia) out of my brain'.* Whereas Louise felt the problem was in her head; she said: *This is where I forget, yeah in my head.* We interpreted these data, which were coded 'dementia', as evidence of 'ontological vulnerability', as they reveal the sense of failing knowledge that people living with this impairment have to deal with routinely.

Participants with dementia frequently articulated a sense of awfulness about their condition, which needs to be understood in the context of social relations and norms. Responsible citizens are expected to be self-sufficient, rational and 'independent'; men in particular, are socialised to be strong, in control, and able to do things for and by themselves. William certainly felt his constant state of anxiety was *'a reaction to being not, not in control'* when he had previously very much felt in control. Similarly, Iain reported a sense of frustration about no longer being able to work out for himself anymore what he is meant to do, as he explained, *'ever since I've had this, this nonsense, let's put it that way, umm it's so strange that you can't, well I can't, I can't fathom out what I've got to do'.* For Frank, who was in his mid-50s and a keen cyclist, it was frustrating because he could no longer go out on his bike on his own anymore. He said: *It's weird, because I can't do it for myself. That's the thing. I can't do it for myself anymore, which is really, really horrible.* Frank did have someone he could go cycling with occasionally; but as he said, *I'd rather go out on my own as that's what I'm used to doing.* Frank likened the experience of no longer being able to do things (like cycling) on his own anymore, as like '*being a little boy again'*, which indicates that ontological vulnerability is gendered. For Frank, having the freedom to go where you want to go was equated to manliness. He said: '*I'm a man, you know I want to go and do what I want to do'.* These comments highlight how normative understandings of masculinity merge with ideas about independence; thus, men like Frank, feel particularly bad when they can no longer do what they were once able to do on their own. Significantly, Frank reported that he had not shared his experiences of getting lost with his male friends, as he thought they were less likely to understand than his wife. He said: *'I haven't spoken to the guys about it, because I, you know, and I mean though they'd probably say to me oh yeah, yeah sometimes you do bloody stupid things that you shouldn't do.* Frank chose not to expose his

vulnerabilities to everyone. Moreover, he reported dealing with it all but not thinking about it. He said *I've blocked it out; you know what I mean, yeah, I mean it's, I wouldn't, I wouldn't go out on my own now*.

Most participants reported dealing with the effects of dementia by staying physically fit, and in particular, walking everywhere. Being able to walk still, despite having dementia and other health problems, was a clear pattern in the phase 2 data. For example, Penelope accepted that she was no longer as sharp mentally, as she once was, but pointed out that this did not make her completely incapable. Like she said: *'I've lost a lot of memory now I've got Alzheimer's. At least I can still get around'*. And when asked at the end of her interview, if there was anything else she wanted to say about going out, she said: *I'm grateful that I can still walk, without pain or anything'*. She knew how important it was to stay physically active. Similarly, Patricia said *'I'm fit but my brain isn't'* and Shaun spoke about his daily walks as an important habit, *'you just got to do it',* he said during his walking interview. Moreover, he felt that walking everyday helped to *'imprint his route into his brain so if his dementia gets worse he won't have to think where to go'*. Also, Nicholas who walked his dog everyday, despite having a hip problem, said: *'But I do still walk. Nothing's stopped me walking'*. Similarly, Joe valued having a tracking device because of *'the walking element that it creates'*. These data show how staying physically active helps people to mitigate the wounding effects of dementia, which is especially important to those like Penelope, Shaun, and Nicholas who are in their 80s and susceptible to other health problems and disabilities. Moreover, they show how older participants were aware of the 'social rule' about being active, and conscious of failing capacities in the brain.

4.2. Vulnerability in public

Participants with dementia reported getting lost outside, which we interpreted as vulnerability in public because people were at risk of harm. One participant - Iain – got lost but he was located and found by the police, as he was carrying a tracking device. The situation began after Iain decided to go out for a while on a Sunday lunchtime in November after having a disagreement with his wife. He took a bus to Winchester and then forgot how to get home. It got dark and the weather took a turn for the worse. He tried to book himself into a hotel but had no luck. Here he describes how he was feeling after a few hours of walking around outdoors, when according to him, it was '*teeming down*'. He said: *I'd just had enough. I was soaking wet….Hungry, feeling sick, at what I'd done to Adeline. I thought she'd never forgive me'*. He went on to say how '*he felt rotten*' for clearing off and leaving Adeline because '*he'd never loved anybody but Adeline*'. Iain was physically and emotionally vulnerable, and he knew it. Such self-awareness is characteristic of ontological vulnerability for persons with early dementia. Thus, when two police officers came towards him and asked him if his name was Iain, he was relieved and gladly went with them to the police station for a cup of tea before being escorted home.

Other participants reported being lost; however, because they were not far from home, they relied on local people for help. For example, Frank told us that he whenever he gets lost he waits for someone who knows him to walk by. As he explained: *well if you don't know where you're going, you might as well just sit down and wait for somebody that walks past and says "Hello Frank, what are you doing here?". "Well I've lost my way again"*. These comments show how someone with a dementia deals with ontological vulnerability in a civic way, by trusting fellow citizens to help. Frank used to be the manager of the local gym and so a lot of people knew him; indeed, during the walking interview several passers-by said 'hello

Frank'. Furthermore, Frank lived in a small village, which he described as *'boring'* and his wife called *'cotton wool land'* – it was a safe place. Thus, waiting for someone in the neighbourhood to assist was a rational and pragmatic way of dealing with getting lost.

Similarly, Penelope did not mind asking other people for help when she got lost, which as her niece explained during the sit-down interview, had happened more than once:

> Detta: *So the first time, you had walked into a shop didn't you, and said I'm lost, I live in [place name]. You remembered that bit. And the lady actually was leaving work, so she brought you here.*
>
> Penelope:*Right.*
>
> Detta: *And another time you went out walking, looking for berries and nature, and you ended up the other side of the pond from this side.*
> Penelope:*Yes.*
> Detta: *And again somebody turned you round and pointed you in the right direction.*
> Penleope:*Yeah.*
> Detta: *You had remembered the name [place name].*

Clearly, members of the public were an important source of assistance for Penelope when she was outdoors; even schoolchildren. Elsewhere during the interview, Penelope reported being caught innocently trespassing 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'*. Significantly, Penelope was aware that in the future she may not be able to ask for help, and was therefore happy to carry a tracking device anyway. She said: *I'm quite confident and I can ask people if I've got lost and things like that, but there might come a time when I'm not being able to respond. And they'll be able to find (the tracker)…so it's very good.*

Other participants with dementia spoke about the fears they had when they were out in public. Often this was because they knew they were no longer able to follow the 'rules' of modern social life (such as, being quick) and/or looked 'vulnerable'. For example, William reported feeling anxious '*right at the word go*' when he goes to withdraw cash. He said: *if there's somebody in the queue, I'll go away. I won't do it.* He was asked if that was because he'd rather not hold people up, to which he immediately responded, *yes*. The fear of delaying others pervaded William's experiences outdoors, which he assuaged by paying using contactless (tap), rather than cash. As he said, *'it's easiest then...if I've got a wallet out and notes, it's an absolute nightmare. And because I know it's a nightmare, I get. More flustered (his wife said first)* which William then repeated. During the walking interview, William was asked what he thought his anxiety was about; he put it down to a dread of not knowing what to do. He said '*I guess it is a fear of being in a position where I am out of control and then in trouble'*. Furthermore, he clearly linked the anxiety that he felt in public with the condition. He said: '*I get nervous around people – (dementia) has done that to me'*. It is clear from these data, that the ontological modes of vulnerability are felt emotionally (as anxiety) and attributed to impairment effects.

Feeling and looking anxious because of the dementia was a real concern for William. Both he and his wife were aware that the visibility of his vulnerability put him at risk in public. For example, when William and his wife were asked about the other factors that were of concern to them when out and about, William immediately responded, '*there is a fear of getting mugged*', because, as his wife went onto say, *'you're looking hesitant and not in control and vulnerable. 'Yeah, yeah',* confirmed William. He was not the only participant to be fearful of crime. Penelope's niece reported that she felt vulnerable to theft, specifically she was '*worried about having her handbag pinched'* and Tom reported concerns about

going out on his own because a friend of his had *'got beaten up very badly'*. Whilst it was not clear from these data why participants feared crime, the feeling that something bad might happen to them was shaping their inner worlds and actions. Indeed, Penelope had come up with her own strategy for dealing with her fears, as her niece explained:

> '*Penelope's came up with the idea of having that [a piece of paper with key names, places and contact numbers on], because I said to her,if something happens to you, nobody's going to know who you are you where you've come from, and that's why she devised the piece of paper in her pocket. I wouldn't have suggested it, because I would have thought she might forget to do that, but because it's her own device, her own thinking, she's remembered that that's important'*.

This is a clear example of how an awareness of failing knowledge is felt emotionally and dealt with civically. In some cases and in certain circumstances, people selected when and with whom they would show vulnerability. Frank's reluctance to tell his male friends about getting lost has already been mentioned. Other participants were reticent about letting other people see that they were carrying a 'special device' – i.e. the tracking technology. For example, Sadie was conscious that the device would signify that something was wrong, which may prompt unwanted questions, and therefore only carried the device when she thought it would help, for example when out walking the dog in case she fell. She did not want to take it with her to the hairdressers. Similarly, Michael chose to conceal his tracking device when he went out, instead he said: *I wear it inside (my coat). You know that's not really visible.* His wife concurred, she said: *'he doesn't have to have that showing anyway when it's tucked in'*.

However, exposure was not always under a person's control. Sometimes other people guessed the person had some kind of impairment or health problem. For example, William thought that the shop assistants in his local store had worked out that he had dementia, even

though he had not told them explicitly; he said: '*The ladies (in the village One-Stop shop) down there, I think they've sussed me'*. In addition, he recalled an awkward time in the shop when he was served by someone who did not know him; as he explained:

> William: *I have been in shops hmm [pause] er where it's not the normal, not the usual shop assistant, and er it's been uncomfortable, significantly uncomfortable.*
> I: *Yeah.*
> William: *Until.*
> I: *For who; who is it uncomfortable for?*
> William: *I think it's for the shop assistant as well.*
> I: *Okay.*
> William: *And on one occasion the normal shop assistant came out from the back and said oh hello William, how're you getting on, and it was, and [pause].*
> I: *Yep.*
> William: *And everything was okay.*

Encounters with other people meant that one's foibles were likely to be exposed; something that William, and other participants in this study seemed prepared to accept and able to deal with. For example, Patricia was not always sure who was greeting her when she was out and about, as she said: '*Well some people say hello Patricia how are you, you know, or hello, and I think who the Hell is that. Memory loss….I have got memory loss.* These accounts show how vulnerabilities in public are shaped by both neurological and relational processes.

4.3 Vulnerability within the family

We found that vulnerability was shared within the family, and between family members; it was not only the person with dementia (or family carer) who felt it, but everyone involved. Take for example, the incident involving Iain getting lost in Winchester. He and his wife were mutually troubled by this incident; they said:

Adeline   But this episode with Winchester, well that really put the wind up me.
I: Yeah.
Iain: And me!
I: Yeah.
Adeline: Yes.
Iain: My God!

Iain getting lost was an experience the couple both shared and were deeply affected by; moreover, it extended to their son who Adeline telephoned for advice about contacting the police. As a result, Adeline felt justified in insisting that Iain wore the device the next time he went out on his own, whether he wanted to or not. As she said: *I made him put it on yesterday, because I went to meet a friend for a cup of coffee and he went for a walk….So I said you must put your alarm on*. Iain obliged, perhaps to show that he cared about his wife's wellbeing, as well as his own – who was after all *'his sweetheart'*. Another married couple, Michael and Julie, also had a shared understanding about using the tracking device. Michael was reluctant to use it but carried it anyway because he knew his wife worried about him if he did not. He said: *It's good for Julie she says I should have one, so I carry it….Just in case I get in trouble*. Michael was not sure how it worked so relied on his wife, as he said: *'Julie will just you know tell me what I'm doing wrong and what I'm doing right'*. In effect, they were both aware of being vulnerable when outdoors, and shared the responsibility of dealing with it; Michael's job was to carry the device, whereas Julie's was to help him to operate it.

Family relationships and practices inevitably change when someone has dementia. Sometimes these can go unrecognised by the family carer. For example, during the sit-down interview with Frank, he and his wife spoke about a time when Frank had got lost. His wife told us: *Yeah, I did lose him*. To which Frank responded: *You do lose me. Because you hadn't looked after me*. Frank and Louise had gone out shopping, a regular activity together, where

they would ordinarily do some shopping together and some separately. This was previously mutually acceptable, and they would wander off from each other and then find each other again. Frank recognised that this no longer worked for him, as his ability to independently separate and reconnect required skills that he recognised as lacking. Louise, on the other hand, was surprised that he was no longer able to do this, and was more reliant on her when out. During the interview, it became apparent that they had needed to discuss this to identify the change that was needed. This exchange shows how ontological vulnerability plays out in family practices. Specifically, it highlights how the person with dementia can be more aware of failing abilities, than their spouse.

Other participants reported how they felt and thought about using the tracking equipment in relation to other family members. Take for example, Penelope who lived alone and used her tracking technology always during the day, and Detta, her niece who lived close by and who tracked Penelope's location at various times during the day. During their sit-down interview, they were asked whether it would be a good idea for Penelope to use a tracker:

> Penelope: Oh you'll track me around, oh yes.
> Detta: If you've gone to Scotland for the day.
> Penelope: A spy in the camp!
> Detta: That's right, that's right.
> I: Okay.
> Detta: Just in case.
> Penelope: Yes.
> I: So what do you think about that, what do you think about using something like that?
> Penelope: Yes, it'll be useful for not only my peace of mind but also Detta, so I think.
> Detta: Yes.

These women had a strong relationship and were therefore able to joke about and share the precarity of their situation. This exchange, and the ones above between spouses, highlight

how it is not always possible to disentangle vulnerabilities between family members, as everyone is affected and feels exposed by the dementia in one way or another.

Family members in particular spoke about the teething problems they had had with the telecare equipment, in a way that suggested it left them feeling exposed. For example, during the sit-down interview with Bernard and Saffron, she explained how they had a lot of phone calls over the weekend from the telehealth care company, because the battery had run down, and a button had not been pressed in response to the medication alert. This led her to feel embarrassed, as she said: *they've been very helpful and very nice and everything, but I just feel guilty, you know for people to keep me phoning me for nothing. They ring, keep ringing us you know every time we do something wrong. I don't really want people to keep phoning us [Laughs].* Saffron was also concerned that if the call centre was not able to contact her or other family members about Bernard, because they were at work and unable to take a call, a situation could escalate. As she said: *'I think it would lead to lots of unnecessary panics, because they were thinking he was lost and he wasn't.* Similarly, Adeline spoke of 'feeling guilty' when the telecare company called them, because the alarm had gone off after the device had fallen off the bed. These accounts of dealing with telehealth workers shows how vulnerable households can become when they have a tracking system installed. In a sense, it exposes the family's dependency on an external agency and lack of control over the situation.

Finally, the data suggest that some experiences are not shared, as the person with dementia becomes in a sense, invulnerable. Family members in particular reported times when they felt exposed or let down in public due to the effects of the dementia. For example, one participant, Bernard, had a habit of whistling whenever he we was out in public, much to the annoyance of other people sometimes. As his wife, Saffron remarked '*we are very noticeable*

in supermarkets these days' [Laughs]. Clearly, this was awkward for her, but not him. Alternatively, maybe the situation was awkward for Bernard, which is why he whistled. For another couple, Michael and Julie, simple pleasures like going out to eat had become problematic because Michael was no longer able to follow the 'rules' associated with that activity. As she 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.* Once again, the person with dementia is more conscious of failing abilities, than their spouse. Clearly, some aspects of dementia are not shareable or even recognised by family members as an impairment effect.

5. Discussion and Conclusion

We began the paper by problematizing the label 'vulnerability' and arguing for more recognition of the shared vulnerabilities and responsibilities of care associated with dementia. By taking a critical disability lens, we have been able to draw out how people with dementia experience and deal with the relational and emotional aspects of vulnerability. In particular, the lens has benefited our interpretations of data on impairment effects; rather than focusing on cognitive decline, we found that the more diffuse 'unfathomable sensations within the self' might be more important to people with dementia. Through a novel methodology of walking interviews with fifteen research participants and an additional sit-down interview with them and their family carer, we identified an unexpected thread of 'ontological vulnerability'- that is, an awareness of failing knowledge about oneself or the 'rules' of outdoor life, which individuals experienced emotionally and dealt with civically - for example, trusting strangers to help. Previous empirical work in ageing studies has found that dementia is a 'breakdown of a deeply embodied sort' (Phinney & Chesla, 2003: 296), and recent research conducted in Sweden shows that people with dementia are willing to trust other people in their neighbourhood (Olsson et al., 2013). Our research concurs with these findings and identifies

an important notion of 'ontological vulnerability', which may help to explain the relational experiences and practices of people with dementia outside the home. Future research could examine the extent to which 'ontological vulnerability' is a factor in people's lives, and seek to identify ways to alleviate it.

Our participants' stories of venturing outdoors challenge the dominant association between vulnerability and weakness in several ways. First, they show how cognisant and open people with dementia are about their changing emotions and circumstances. Participants in their 50s and 60s knew that they could no longer do things safely on their own anymore, whilst participants in their 70s and 80s were conscious that their general health could deteriorate at any time. Second, stories of life outdoors related explicitly to other people and technologies, as well as certain places. Family members, police officers, shop workers, friends, acquaintances, and strangers all contribute to a person's sense of ontological vulnerability, as do place-inscribed rules (such as being quick at a cashpoint). As such, participants were selective about where and with whom they would interact and/or carry their GPS device, as they knew they risked exposure. It is argued that 'such is the stigma of the disability label that many disabled people deny or seek to hide their impairment' (Kitchin, 1998: 352). We found that participants tried to manage, and sometimes conceal, the challenges they faced so as not to attract the feared evaluation of deterioration. However, we found too, that participants were keen to discuss and negotiate the help required to find solutions to practical and emotional challenges, but were unsupported to do so, as others were not aware of how the changes imposed by dementia had affected everyday activities that they hoped to continue. Finally, the need to understand dementia in the context of gender relations, which other scholars recommend, is evident in our study (e.g. Sandberg, 2018). Male participants

were willing to relinquish control to their wives, whilst female participants were prepared to adapt to changing familial dynamics.

Study findings have significant implications for global policies related to 'dementia-friendly' communities. To date, work in this area has either focused on the built environment (e.g. Fleming, Bennett, Preece, & Phillipson, 2017), or it has been conceptual and defined or critiqued the notion of 'dementia-friendly' (e.g. Lin & Lewis, 2015). Our study indicates that future work should examine the micro practices of persons with dementia who live in a 'dementia friendly community', as this is where vulnerability is situated and opportunities for inclusion and empowerment are located.

Experiences of vulnerability locate some of the challenges related to the impairments caused by dementia. We found that people with dementia, their families and others are often aware of different levels of decline, or varying (and sometimes unusual) sorts of challenges – such as whistling in public. Critically, we found that family members share some of the processes of vulnerability associated with dementia (such as getting lost when outdoors). This has implications for practice. Notably, practitioners need to acknowledge and support people's vulnerability outdoors in a family-orientated way when risk planning. The relational aspects of risk planning are well documented in dementia studies (see, for example, Bailey et al., 2013); what this study foregrounds is the inner emotions and monologues of people with dementia when they are out and about on their own, and with family members.

This research did have several limitations, including the relatively small sample size, and self-selecting participants. There was a predominance of men in the sample, and that may

reflect that independence is viewed as more important for men than women when considering who may benefit from 'tracking' technologies and this could be investigated further in another study. Another limitation was the study setting, which was geographically specific. Hence, there are no data from people living in an inner city, which may have uncovered other meanings and processes of vulnerability.

In conclusion, the paper demonstrates the value of prioritising the experiential knowledge and inner monologues of people with dementia. A focus on how men and women with dementia actually experience the outside world, and deal with the processes of vulnerability that that entails, sheds important new light on impairment effects and the adjustments that need to be made at familial and societal levels. Tolhurst et al (2018) remind us to 'convey the concrete actuality of experience, rather than aprioristically counter particular sociocultural representations' (Tolhurst et al., 2018: 13). This study has shown that people with dementia are aware of and actively negotiate vulnerabilities, and that these vulnerabilities are associated with an acquired health status. These are often new experiences, and people with dementia develop new strategies and evolve emotional and material responses to cope. In relational terms, this enables responses that are more open and shared so that a constructive dialogue may happen that brings people together rather than creating opposing and competitive needs. From a citizenship perspective, it shows how people with dementia are able to take responsibility for themselves and create other ways of being in the outside world (for example, normalising dependence on strangers). Understanding vulnerabilities within interdependent relations challenges the positioning of people as more and less vulnerable and dependent and acknowledges the shared contributions that people have made throughout their lives to relational dependency.

References

Bailey, C., Clarke, C. L., Gibb, C., Haining, S., Wilkinson, H., & Tiplady, S. (2013). Risky
and resilient life with dementia: review of and reflections on the literature. *Health, Risk*
& Society, *15*(5), 390–401. https://doi.org/10.1080/13698575.2013.821460

Bartlett, R. (2012). The emergent modes of dementia activism. *Ageing and Society*, *34*(04),
623–644. https://doi.org/10.1017/S0144686X12001158

Beard, R. L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we
reframe dementia through personal narratives. *Journal of Aging Studies*, *23*(4), 227–235.
https://doi.org/10.1016/j.jaging.2008.01.002

Beckett, A. E. (2005). Reconsidering Citizenship in the Light of the Concerns of the UK
Disability Movement. *Citizenship Studies*, *9*(4), 405–421.
https://doi.org/10.1080/13621020500211412

Beckett, A. E. (2006). *Citizenship and Vulnerability: Disability and issues of social and*
political engagement. London: Palgrave Macmillan.

Behuniak, S. M. (2010). Toward a political model of dementia: Power as compassionate care.
Journal of Aging Studies, *24*(4), 231–240. https://doi.org/10.1016/j.jaging.2010.05.003

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of
care. *Dementia*, *15*(3), 304–314.

Brittain, K., Corner, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of
place: The lived experience of people with dementia in changing social, physical and
technological environments. *Sociology of Health and Illness*, *32*(2), 272–287.
https://doi.org/10.1111/j.1467-9566.2009.01203.x

Cahill, C. (2018). *Dementia and Human Rights*. Bristol: Policy Press.

Calhoun, C., Garry, A., Lugones, M., Binghamton, S., Narayan, U., College, V., Dodds, S.
(2014). Vulnerability: New essays in ethics and feminist philosophy. Oxford: Oxford
University Press.

Carpiano, R. M. (2009). Come take a walk with me: the "go-along" interview as a novel
method for studying the implications of place for health and well-being. *Health & Place*,
15(1), 263–272. https://doi.org/10.1016/j.healthplace.2008.05.003

Department of Health. (2009). Living well with dementia : Dementia. *Living Well with
Dementia A National Dementia Strategy*, *2009*, 2009. igitalasset/dh_094051.pdf

Duggan, S., Blackman, T., Martyr, a., & Van Schaik, P. (2008). The impact of early
dementia on outdoor life: A `shrinking world'? *Dementia*, *7*(2), 191–204.
https://doi.org/10.1177/1471301208091158

Eriksen, S., Helvik, A. S., Juvet, L. K., Skovdahl, K., Førsund, L. H., & Grov, E. K. (2016).
The Experience of Relations in Persons with Dementia: A Systematic Meta-Synthesis.
Dementia and Geriatric Cognitive Disorders, *42*(5–6), 342–368.
https://doi.org/10.1159/000452404

Fleming, R., Bennett, K., Preece, T., & Phillipson, L. (2017). The development and testing of
the dementia friendly communities environment assessment tool (DFC EAT).
International Psychogeriatrics. https://doi.org/10.1017/S1041610216001678

Garcia, C. M., Eisenberg, M. E., Frerich, E. a, Lechner, K. E., & Lust, K. (2012). Conducting
go-along interviews to understand context and promote health. *Qualitative Health
Research*, *22*(10), 1395–1403. https://doi.org/10.1177/1049732312452936

Given, L. (2008). *Sage Encyclopedia of Qualitative Methods*. (L. Given, Ed.). London: Sage

Publications.

Grenier, A., Lloyd, L., & Phillipson, C. (2017). Precarity in late life: rethinking dementia as a
'frailed' old age. *Sociology of Health and Illness*, *39*(2), 318–330.
https://doi.org/10.1111/1467-9566.12476

Kitchin, R. (1998). "Out of Place", Knowing one's place': space, power and the exclusion of
disabled people. *Disability & Society*, *13*, 343–356.

Kusenbach, M. (2003). Street Phenomenology. *Ethnography*, *4*(3), 455–485.
https://doi.org/10.1177/146613810343007

Landau, R., Werner, S., Auslander, G. K., Shoval, N., & Heinik, J. (2009). Attitudes of
Family and Professional Care-Givers towards the Use of GPS for Tracking Patients with
Dementia: An Exploratory Study. *British Journal of Social Work*, *39*(4), 670–692.
https://doi.org/10.1093/bjsw/bcp037

Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia
positive: Concepts to prepare for the future. *Gerontologist*, *55*(2), 237–244.
https://doi.org/10.1093/geront/gnu122

Luna, F. (2009). Elucidating the concept of vulnerability: Layers not labels. *International
Journal of Feminist Approaches to Bioethics*, *2*(1), 121–139.

Manthorpe, J., & Martineau, S. (2016). Serious Case Reviews into Dementia Care: An
Analysis of Context and Content. *British Journal of Social Work*, *46*(2), 514–531.
https://doi.org/10.1093/bjsw/bcu135

McNess, A. M. (2017). Personhood and Vulnerability: Understanding Social Attitudes
Towards Dementia. *Ethics and Social Welfare*, *11*(4), 398–403.
https://doi.org/10.1080/17496535.2017.1396483

Oderud, Tone; Landmark, Bjorg; Eriksen, Sissel; Fossberg, Anne Berit; Aketun, Sigrid;
    Omland, May; Hem, Karl-Gerhard; Ostensen, Elisabeth; Ausen, D. (2015). Persons with
    Dementia and their Caregivers using GPS. *Studies in Health Technology and
    Informatics*, *217*, 212–221.

Olsson, A., Lampic, C., Skovdahl, K., & Engström, M. (2013). Persons with early-stage
    dementia reflect on being outdoors: a repeated interview study. *Aging & Mental Health*,
    17(7), 793–800. https://doi.org/10.1080/13607863.2013.801065

Phinney, A, Chesla, D. (2003). The lived body in dementia. *Journal of Aging Studies*, *17*,
    283–299.

Reason, P. (1994). *Participation in Human Inquiry*. London: Sage.

Sandberg, L. J. (2018). Dementia and the gender trouble?: Theorising dementia, gendered
    subjectivity and embodiment. *Journal of Aging Studies*, (xxxx), 0–1.
    https://doi.org/10.1016/j.jaging.2018.01.004

Sandberg, L., Rosenberg, L., Sandman, P.-O., & Borell, L. (2015). Risks in situations that are
    experienced as unfamiliar and confusing - the perspective of persons with dementia.
    Dementia (London, England), *0*, 1–15. https://doi.org/10.1177/1471301215603836

Smebye, K. L., Kirkevold, M., & Engedal, K. (2015). Ethical dilemmas concerning autonomy
    when persons with dementia wish to live at home: a qualitative, hermeneutic study.
    BMC Health Services Research, *16*(1), 21. https://doi.org/10.1186/s12913-015-1217-1

Timmermans, S., & Tavory, I. (2012). Theory Construction in Qualitative Research: From
    Grounded Theory to Abductive Analysis. *Sociological Theory*, *30*(3), 167–186.
    https://doi.org/10.1177/0735275112457914

Tolhurst, E., Carey, M., Weicht, B., Kingston, P., Tolhurst, E., Carey, M., … Weicht, B.

(2018). Is living well with dementia a credible aspiration for spousal carers ? *Health Sociology Review*, *0*(0), 1–15. https://doi.org/10.1080/14461242.2018.1475249

Turner, B. S. (2003). Biology, vulnerability and politics. In G. Williams, S; Birke, L and Bendelow (Ed.), *Debating Biology: Sociological reflections on health, medicine and society*. London: Routledge.

Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., … Keady, J. (2017). The lived neighborhood: understanding how people with dementia engage with their local environment. *International Psychogeriatrics*, (May), 1–14. https://doi.org/10.1017/S1041610217000631

Wiles, J. (2011). Reflections on being a recipient of care: vexing the concept of vulnerability. *Social & Cultural Geography*, *12*(6), 573–588. https://doi.org/10.1080/14649365.2011.601237

World Health Organisation. (2017). Draft global action plan on the public health response to dementia: Report by the Director - General, (December 2016), 1–29. Retrieved from http://apps.who.int/gb/ebwha/pdf_files/EB140/B140_28-en.pdf?ua=1

World HealthOrganisation. (2012). *Dementia: A public health priority*.