**Inclusive (social) citizenship and persons with dementia**

Bartlett, Ruth

Orcid ID: 0000-0002-3412-2300

School of Health Sciences, University of Southampton, UK

Ruth.louise.bartlett@vid.no

@RuthLBartlett

# Points of interest

# Access to the outside world is important for disabled people, including people with dementia.

# This study examined the outdoor experiences of 15 persons with dementia living at home in southern England, to find out what access means for someone with a neurological condition.

# This study found that access work involved ‘access to location technologies’, ‘access to ordinary places’, and ‘consciously sharing the responsibility of access work’.

# The study shows how important it is to take account of cognition when promoting access rights for disabled people, including people with dementia.

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**Abstract**

This article aims to advance knowledge of inclusive (social) citizenship, through an empirical analysis of the access work of persons with a dementia. Drawing on the notion of cognitive accessibility and empirical data collected in Southern England using a novel methodology of go-along walking interviews with 15 people with dementia followed by a sit-down interview that included a nominated family member, this paper examines how persons with dementia access the outside world. The study found that access work entailed three spheres of activity: ‘access to location technologies’, ‘access to ordinary places’, and ‘consciously sharing the responsibility of access work’. Overall, this article contributes to the growing literature on cognitive accessibility by evidencing the mental demands of access work, as experienced by people with dementia, and need to share the responsibility of access work between humans and non-humans, and state and non-state actors.

# Introduction

This article is concerned with advancing knowledge of cognitive accessibility in the context of inclusive citizenship, and in particular, social citizenship. Inclusive (social) citizenship is about recognition of difference and the multifarious ways in which social rights and responsibilities are exercised in everyday life (Lister 2007). The idea urgently needs to evolve for persons with a dementia - one of the fastest growing subgroups of disabled people in the world. Dementia is a major cause of cognitive disability affecting over 50 million citizens worldwide; it is a progressive neurological condition that alters a person’s higher cortical functions, including language and communication, organisation, reasoning and reflection, all the human qualities on which being a ‘good civic-minded citizen’ depends (Smith, 2019). Evidence is mounting that people diagnosed with this condition struggle to cope with everyday life (Bjørkløf et al. 2019), feel stigmatised and marginalised (Bhatt et al. 2019) and experience life with dementia as like ‘living in space where the walls keep closing in’ (Førsund et al. 2018: 1). Dementia poses a monumental threat to (social) citizenship. Even so, persons with dementia have been largely overlooked in disability studies. This article aims to focus on the access work of persons with dementia who live at home, so that understandings of inclusive (social) citizenship can develop further (Beckett 2005).

Access is a key element of inclusive (social) citizenship for disabled people. Access is essentially the ‘ability to benefit from things’ such as material resources, places and opportunities (Ribot and Peluso 2009: 153). It is an important and long-standing goal in disability studies, where considerable attention is paid to access to the built environment (e.g. Imrie & Kumar, 1998), education (e.g. Nind & Seale, 2009), paid work (e.g. Weston, 2004) and public transportation systems (e.g. Asplund, Wallin, and Jonsson 2012). Work on the built environment is especially strong and typically draws on the notion of universal design – ‘a movement to produce built environments that are accessible to a broad human variation’ (Hamraie, 2013: 1). This body of research has drawn attention to not only matters of structural accessibility but also how vulnerability and disability are an integral part of human life (Lid 2015). Access is important, then, from an inclusive (social) citizenship perspective, as many disabled people are unable to access what that they need to participate in life, and can feel excluded as a result (Corazon et al. 2019).

In this paper, the idea of inclusive (social) citizenship is aligned with access, and in particular, ‘cognitive accessibility’ (Steel and Janeslätt 2017). Cognitive accessibility is defined as ‘the extent to which products, systems, services, environments and facilities can be used by people from a population with the widest range of cognitive characteristics and abilities to achieve a specified goal in a specified context of use’. In recent years, cognitive accessibility has gained traction in disability studies, as evidenced by the development of international standards for cognitive accessibility and calls for ‘cognitive ramps’ such as the ‘modification of pace’ (Yalon-Chamovitz, Shach, Avidan-Ziv, & Tenne Rinde, 2016: 455). Using the idea in relation to persons with dementia, highlights the cognitive elements of both access work and inclusive (social) citizenship.

Discussion draws on empirical data collected in southern England for a qualitative study about the use of GPS location technologies by persons with dementia. Access work was identified as a core theme in participant’s accounts: access to the GPS location technology; access to ordinary places; and access as a consciously shared responsibility (Bartlett and Brannelly, 2019). Before analysing people’s access work in detail, the latest social research on dementia is discussed in the context of inclusive (social) citizenship to elaborate on how these topics are currently conceptualised and applied in dementia research and policy.

# (Social) citizenship and persons with dementia

(Social) citizenship, as a core consideration in understanding and responding to the experience of dementia has gained increasing currency over the past decade in dementia studies (Bartlett 2016). Dementia researchers have used it to examine the narratives of persons with dementia (e.g. Baldwin 2008) and policy debates (Nedlund and Nordh 2015); and to highlight the discrimination that persons with dementia can face when they need medical treatment (Graham 2004). Typically, the idea of citizenship is deployed to draw attention to the ‘visibility, voice and inclusion of people with dementia in health service provision’ (Gilmour and Brannelly 2010: 245) and people’s requirement for ‘assisted autonomy’ (Boyle 2008: 530) and respect for human rights in care environments (Kelly and Innes 2013; Cahill 2018). Not all scholars use the language of citizenship, but are nonetheless concerned with cognate matters, such as power relations (e.g. Beard, Knauss, and Moyer 2009, Behuniak 2010), social inclusion (e.g. Hicks, Innes, and Nyman 2019), and access (e.g. Brorsson et al. 2011).

Some researchers have used the term ‘relational citizenship’ to examine care dynamics involving people with dementia (e.g. Kontos, Miller, and Kontos 2017). As Pols (2016) explains, ‘relational citizenship assumes that people become citizens through interactions, whereby they create particular relations and social spaces….citizenship (thus) becomes a matter of sociality’ (Pols 2016: 177). This idea has been used to examine how ‘care-collectives’ work within families and care institutions to ‘act and produce citizenship’ (Ursin and Lotherington 2018: 62). Such work usefully examines the connections between various agents, including persons with dementia; however, it is important not to lose sight of wider society and its organisations. Hence, the notion of *social* citizenship is used in this article.

Social citizenship typically focuses on a person’s relationship to the ‘larger structures of rule and belonging, which are often but not exclusively nation states’ (De Koning, Jaffe, and Koster 2015: 121). These dynamics are perhaps most evident in discussions about access to healthcare; an area that continues to be regarded by many as a central tenant of inclusive social citizenship (Dwyer 2002). According to Dwyer (2010), there are three main channels of social citizenship (1) provision – the institutions providing welfare (2) conditionality – the relationship between rights and responsibilities and (3) membership – groups who are included/excluded from welfare arrangements (p.278). Each one is significant for persons with dementia. For example, in one of the largest transnational studies of access to health care services by people with dementia and their family care partners, researchers concluded that ‘barriers to accessing and using formal care still exist across Europe despite a number of national and European initiatives’ (Stephan et al. 2018: 2). Evidently, a disjuncture exists between policy intent and what actually happens in practice. Other national studies have found that black and minority ethnic people with dementia are generally under-represented in dementia services (Moriarty, Sharif, and Robinson 2011); and younger people with dementia lack the age-appropriate services to access (O’Connor, Phinney, and Hulko 2010; Roach and Drummond 2014). Collectively, this work suggests that provision, conditionality, and membership are major, ongoing problems for persons with dementia.

In sum, the concept of (social) citizenship has been instrumental in transforming dementia from an individual healthcare matter into a subject of wider social concern, especially when it comes to access and accessibility.

***Access to places and resources***

In recent years, interest in how persons with dementia access and negotiate outdoor places has grown enormously. As a result, knowledge is expanding about people’s relationships in, and to their local neighbourhoods (e.g. Duggan, Blackman, Martyr, & Van Schaik, 2008; Keady et al., 2012; Beard, 2016; Eriksen et al., 2016). This area of research includes the experiences of immigrants (Antelius 2017), as well as younger people with dementia (Phinney et al. 2016). As such, questions of provision (i.e. from where is welfare sourced?) and membership (i.e. who meets the in/formal rules of belonging?) are becoming more critical in dementia studies.

Access to the outside world is a matter of inclusive (social) citizenship for persons with dementia. This is evidenced by findings from one of the largest ethnographic studies of neighbourhood relations carried out across multiple study sites in England, Scotland and Sweden. Researchers found that the ‘neighbourhood provides a significant arena for people to draw upon their personal potential and capabilities in order to compensate for the limitations they experience’ (Ward et al. 2017: 11). This is an important point, as it unsettles a commonly held assumption in the context of persons with dementia, namely that care is provided by care providers in care settings. The same study found that ‘people living alone with dementia manage their neighbourhood social relations in ways that maintain their capacity to live independently in the community’ (Odzakovic et al. 2019: 20). Given the focus on couples/dyads in dementia (care) research (e.g. Nolan et al. 2002) and tendency to overlook the agency of persons with dementia (Boyle 2014), this too, is a critical finding. It renders visible, the micro-ways citizens with dementia, exercise their social rights and responsibilities in everyday life.

The matter of social rights and responsibilities is evident in dementia studies and includes empirical work on access to outside places and resources, including technologies. For example, a research team in Sweden have argued that persons with dementia are at risk of ‘occupational injustices and alienation’ because cognitive differences are not considered in the context of everyday technology access and use amongst older adults (Kottorp et al. 2016: 386). In an earlier study conducted in England, people with dementia and their carers were invited to talk about their views of accessing outside spaces; researchers found that people with dementia ‘can sometimes feel out of place in outside space…. And technologies can support or hinder access’ to the outside world (Brittain, Corner, Robinson, & Bond, 2010: 283). This work raises important questions of provision, conditionality, and membership – not least, who (or what) is responsible for ensuring a person’s access rights are upheld, safely?

Access to resources and places is not without its risks for people with dementia, due to the nature of the impairment. A person living with dementia often relies on others to intervene and engage a complex interplay of resources to manage ‘risky situations’ (Bailey et al. 2013: 391). For example, the police are increasingly involved in ‘social emergencies’ involving persons with dementia who have gone out for a walk and got lost (Brown et al. 2014: 2191). As Bantry White and Montgomery (2015) explain: getting lost is a ‘low-frequency event for people with dementia but for a small minority, the risks are considerable’ (p.224). To mitigate such risks, in some countries, including the UK, USA, and Norway, the police and/or welfare providers issue Global Positioning System (GPS) location technologies to people with dementia and their family carers. To date, the lens of citizenship has not been used to explore this practice, even though it clearly applies, as one can ‘imagine, perceive and locate the state in people’s everyday lives’ (Yalçin-Heckmann 2011: 435). Hence, in this article, the access work of persons with dementia is examined through the lens of inclusive (social) citizenship.

**Methods and Data**

The empirical research that generated this article explored the use of GPS location

technologies by people with dementia living at home from multiple perspectives,

including the police, people with dementia and their family care partners. When the

study began in 2016, participants with dementia ranged in age from 55 to 85; everyone

had capacity to consent to take part in the study, went outdoors virtually every day and

used some form of location technology. Ten participants used an Oysta Pearl – a

mobile device with an inbuilt one touch SOS emergency button, fall sensor, and GPS

location tracking function. Three participants used their Smartphone and one

participant used a GPS-enabled key fob. Thirteen participants lived with their spouse; two lived on their own. Note, the names used in this article are not real names

Data were collected for six months between November 2016 and April 2017 using go-along walking interviews followed by a sit-down interview with a family member. The mobile method of a go-along walking interview is particularly suited to understanding how people use location technologies and access public spaces, because the data generated whilst walking is informed by the environment (Evans & Jones, 2011) and the embodied nature of knowledge becomes observable (Doughty, 2013). As disability scholars argue, ‘accessibility comprises a personal as well as an environmental component, and that accessibility must be analysed by an integration of both’ (Iwarsson and Ståhl, 2003: 57). The methodological approach used in the study enabled this.

Twenty-seven individual go-along walking interviews were conducted with 15 people with dementia (10 men and 5 women). Thirteen people consented to two walking interviews; one participant consented to only one. In each case, the route was determined by the participant rather than the researcher. Some walks were longer than others were. The shortest walk was 0.33 miles and took seven minutes. Longer walks were around three miles, and lasted closer to 60 minutes. After each ‘go-along’ walking interview, the researcher completed an observation form based on the themes identified by ethnographer Margarethe 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 observations were stored and coded as part of the data set.

Go-along walking interviews were followed by a sit-down interview with the person with dementia and their nominated family member. 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. Participants were recruited via Admiral Nurses (who provide specialist dementia support to families), Memory Service Occupational Therapists, and Alzheimer Society and Mind Dementia Advisers. 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).

**Data management and analysis**

The interviews were transcribed by a professional transcriber and the dataset was managed using the qualitative software programme NVivo version 11. Data analysis was abductive in that it incorporated both the dataset and relevant theoretical concepts (Timmermans & Tavory, 2012) – including social citizenship. The process involved a systematic process of immersion, organising, coding and interrogating the data, and identifying salient themes and concepts. A thematic coding framework was developed using codes created from the data and from the teams’ disciplinary perspectives. 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 the author and another member of the research team 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. A process that led to the identification of ‘access work’ as a core category.

**Access work**

***Access to location technologies***

During the sit-down interviews, participants were asked about their experiences of

trying to access a GPS location device. Responses were mixed. 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. As Fiona (a family carer) said: *We were*

*put on a listing, and they were going to send some, er, administrative, umm, paperwork*

*through, to put us on. And nothing.* These excerpts show the lived realities of

membership, as service providers get to decide who has access to this particular

resource and when.

Other participants, who had accessed a GPS device relatively easily, reported that they had to figure how it worked for themselves, as no one took the time to explain it to them. For example, Tom’s wife - Ali (who was dealing with her own mental health issues) - described the initial set-up as too fast, with little information. She said, ‘*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].* The couple told us that they thought the people who set the device up assumed they had knowledge that they did not have. Hence, they relied on the instruction booklet for further information, or simply did not use all the functions. During the same interview, Tom was asked what the big blue (SOS) button in the middle was for, but he did not know, as he said: *I don’t know what that is actually. I’ve not got round to sort of like fathoming that one out.* These data show the cognitive side to access work, and highlight the need for technical support to mediate full access – that is, benefiting from *all* the features of this resource.

Of the 15 participants using a GPS location device, five carried the device passively - that is, they were unable to use the phone function or SOS button. Two users said that they would use the SOS should they need it. Four users responded to calls from family on the device, and four users used the phone to contact family. Thus, even in this relatively small sample the value of the resource to persons living with dementia varied considerably. For example, two of the participants with dementia found the GPS location technology very beneficial; it effectively saved their life. Iain (who had got lost and was found by the police) described it ‘as a boon’ and Tom described it as ‘brilliant’, adding that ‘the police really love it’ because he too had gone missing, but was easily found via the tracking system. In both cases, access relations were seemingly working well.

Other participants were less convinced of the benefits of using a GPS location device; for 55 year-old Frank, the device was too cognitively demanding, as he said: ‘there’s too much for me to do’, and 75 year-old Michael usually left his device on the sideboard when he went out for a walk, as he ‘felt the operation of it was a bit hit and miss’. These data suggest that functionality is a key mechanism by which different people derive gains from a GPS location technologies; if the resource does what it is meant to do – namely, locate a person when they need to be located, it is more likely to be perceived as beneficial.

In some cases, the provision of the location technology seemed to *create* access problems rather than alleviate them. Typically, this was because the authorities lacked a proper understanding of a person’s circumstances, and the technology was not personalised accordingly. Take for example, Bernard who has Primary Progressive Aphasia, a type of dementia, which impairs language centres. He and his wife – Saffron, who still worked part-time as a teacher - had been offered an Oysta Pearl but she was hesitant about accepting it. As she explained, ‘if Bernard rang the call centre by mistake and I’m not here, they would think it was an emergency (because Bernard would not be able to explain that he had called by mistake). They would then have to send somebody to the house or try to contact me at work. It would escalate really quickly…and I don’t think that’s appropriate most times’. Hence, even though they could access a device, they were hesitant about doing so, because of the perceived lack of understanding concerning their circumstances.

Another participant found the geo-fencing functionof the location technology confusing and unnecessary. Possibly because it felt like an invasion of his privacy (White and Montgomery 2014). 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? This episode highlighted how other people (e.g. family members and telehealth care workers) assume responsibility for defining the places a person can safely access rather than the person with dementia themselves. Therein denying the person with dementia a chance to exercise social citizenship.

A lack of opportunities to practice social citizenship was not a universal experience for participants. Some participants reported using a more basic form of location technology - a help card-either in addition to their GPS device or instead of, to stay in control. For example, Penelope, who lived alone, told us that she always carried her help-card *‘In case of emergency’* card, as she said: ‘*I carry that in my pocket. Everywhere I go*’. Similarly, Ali and Tom reported that he always carried his Alzheimer’s card in case he got lost.

For these participants, the card was an essential resource and carrying it all the time was an important responsibility. Another family member, Karen, thought the cards were a good idea too. As she said: *lots of people find those quite useful, in terms of if they do get stuck you can just kind of present it to somebody so that they can just slow down and take a minute with you’.*  In effect, the card functions as a‘cognitive ramp’ in that it enables people with dementia to access ordinary places, without fear of derision.

***Access to ‘ordinary’ places***

Each study participant with dementia was asked what motivated them to go out; the reasons people gave were the same reasons that anyone else might give for going out. They included, going to the shops, to post letters, fishing, car boot sales, going to the hairdressers, walking the dog, meeting friends for coffee, blackberry picking, to feed the ducks, to sit outside near the sea, and to visit church. One male participant - Joe - said he went out ‘to get a bit of space, and get out of the wife’s way’. Only one person mentioned anything related to health status, and that was Iain who went out for a hospital appointment. Clearly, access to ordinary places is as important to people with dementia, as it is to anyone else.

In the early phases of dementia, impairment effects are often hidden, making it difficult for others to understand why someone might have a problem with access. Even spouses may not recognize the access work required. 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.* Similarly, during the interview with Iain and his wife we learnt from his wife that he could no longer do the shopping; Iain explained why not. He said: *‘I find it difficult to put things in order’*. These extracts suggest that even when physical access is possible, the benefits of a place or opportunity will not be realised, unless cognitive accessibility is recognised as such.

Social relations are central to virtually all elements of access’ (Ribot and Peluso 2009: 172). For persons with dementia, they are the bedrock of cognitive accessibility. For example, Iain reported how he used to go out on his own but ‘I’d be too scared now’ he said. To which the interviewer responded ‘would you, what would you fear?*’* ‘Well people not being patient enough to do things, if something happened’. As he went on to explain, he lacked confidence in himself as much as other people. He said: ‘I’m getting to the stage where I can’t, I’m not confident about doing what I want to do. When asked, in what way, he responded: like forgetting my PIN number on my phone, and a card. This participant was aware of the social responsibility/pressure ‘to remember’ but could not trust either himself or others to achieve this access goal.

Elsewhere in the dataset, it was clear how other people were vital for ensuring cognitive accessibility. Often it was to make certain that access to a place was either legal or logical. 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’.* As she pointed out, physical access was not the problem ‘*I just walked to the copse and up through a gate that was open’.* It was cognitive access – she didn’t *know* she was on private property. Of course, anyone can make this mistake, but for a person with dementia it is perhaps more likely to happen, as access to outdoor places invariably requires cognitive skills.

Logic is a largely unrecognised aspect of access work: it is assumed that a person’s access choices are legitimate and reasonable. This was not always the case for participants in this study. For example, Tom and Shaun, both had problems using their local bus route: Tom got on the correct number bus, but it was going in the wrong direction for him, whereas Shaun did not know which bus stop to alight from, so he stayed on until the final stop. Both men were picked up by the police, after their wives reported them missing. Tom was wearing his tracker so it was relatively easy for them to locate him; Shaun was not so it required an extensive search by two police forces. These practices underline the importance of *cognitive* accessibility for persons with dementia, for whom access is a sensorial matter for the mind, as wellthe body. Furthermore, they show how important it is for disability scholars to recognise greater neurodiversity in how humans access the material and social world (Alper 2018).

***Consciously sharing the responsibility***

Previous research published in this journal has found that interdependent relations are key to realising inclusion and citizenship for people with dementia, especially in regard to decision-making (Keyes, Claire and Gibb 2019). Typically, the emphasis in this work is on human relations and interactions between care partners (see, also, Webb 2017). However, in this study, the responsibility of access work was consciously shared between not only traditional care providers, but also the police, as well as material objects, such as a location technology.

We have already heard how the responsibility of maintaining Tom’s identity as a rule-abiding citizen was shared materially (with the location technology) and relationally (with his wife and the local police). Other participants underlined the value of knowing people in their local neighbourhood, so the responsibility of access work could be shared collectively by community members. . For example, Heather who was in her 80s, had a tendency to get lost when she went out; hence, her family had set up their own community care system. Her husband explained how it worked, he said:

*My son dropped a piece of paper in the other day to the local shop and the umm church and the neighbour, two neighbours here, explaining that Heather has Alzheimer’s and umm, and umm if they could, mind you they’ve all brought her back once or twice. I think she’s walked by the door and they’ve just walked out and said here you know you’re going too far, and brought her back here…..*

Interviewer (I): so there’s some help going on around

*Yes the people at the WI (Women’s Institute) and the church. And there’s quite a few that go to the WI go to the church as well, so they keep an eye on her you know.*

Heather’s family effectively enlisted other citizens and institutions in the civic sphere, including neighbours, shopkeepers, the church, and WI, to provide a system of support. Collectively, and seemingly without conditions, they took responsibility for Heather’s wellbeing and social right to access her local community. This, in turn, promoted Heather’s social citizenship, as she was able to access local services and amenities.

Modern conceptualisations of citizenship are rooted in the belief that it is only through ‘webs of relations’ that access to rights and resources become realisable (Netz et al. 2019: 647). For disabled people, such relations must ‘acknowledge and value a disabled identity’ for enablement and inclusivity to be realised (Robinson, Roberts and Daly, 2007: 175). Several participants reported on how well this can work. For example, as well as Heather, Rose, who had lived in the same house for over 18 years, was able to rely on others to take responsibility for her when she went out; as her daughter explains:

*‘(Rose) knows lots of the neighbours who have been there for a long time. They also know the local bus driver who drives the hopper, and who will direct J in the right direction if she needs it. J does go round a second time if she misses her stop the first time. Neighbours have also helped her get back’.*

Thanks to her neighbours and the local bus driver, Rose continued to go out. Other participants, such as William, relied on friends to ensure they didn’t get lost when they went out. As William’s wife explained: *one of (his friends) told me well somebody’s always on duty when you go to the loo, to make sure you’re alright.* *Yeah, yeah*, William concurred. Significantly, she used the language of ‘duty’, suggesting an awareness of one’s responsibility as a citizen to take care of others (Takkac and Akdemir 2012).

Access theorists contest that ‘access is achieved via social relations of friendship, trust, reciprocity, patronage, dependence and obligation’ (Ribot and Peluso 2009: 172). Typically, such relations are between humans, as in the above examples, but this was not always the case. One participant, Nicholas – who was in 80s, consciously shared the responsibility of getting home safely with his dog. During one interview, he described how much he enjoyed going out with his dog and would call for the dog ‘*automatically*’ and trust him to take him home if he ever got lost. He said, ‘*(the dog’s) ever so good, he never loses track of you’*. Here, access work seemed more instinctive than cognitive, because of the dog. Similarly, Rose had a dog, and her husband seemed less concerned about her getting lost when she went out with it, perhaps because he knew she didn’t have to think too much about where she was going; he said:

*She walks the dog, she’s got two little routes. She goes down the road, sometimes she’ll turn the corner, and you see there’s a flat over here, it’s not a very big flat, I don’t know if you can see it, and she’ll turn round and she’ll come back and then she’ll go down to the bin, if the dog’s done anything, and usually turn around and come back.*

**Limitations**

This study has limitations, including the relatively small sample size, lack of cultural diversity and predominance of men in the sample. In addition, the geographically specific study setting resulted in a bias towards rural communities. All of which means that findings cannot be compared or generalised to other localities or disabled groups.

**Conclusion**

In this paper, it is argued that for persons with dementia, inclusive (social) citizenship is rooted in the recognition and practice of access work, and in particular, the apprehension of cognitive accessibility. Disability scholars have focused on the physical aspects of access and overlooked the more complex mental demands that the process entails, like logical thinking. There is a general assumption in disability studies that citizens have rational subjectivity and the capacity to accept the fundamental responsibilities of social citizenship, such as knowing when and how to access services. However, as this study shows, inclusive (social) citizenship in the context of dementia, inevitably involves the conscious sharing of responsibilities between people, technological things, even animals; hence, there is justification to ‘move beyond the human in pursuit of equality and justice’ for persons with dementia (Jenkins, 2017:1). A conceptual move that is evident and welcomed in critical disability studies (Goodley, Lawthom, and Liddiard, 2019).

A post human agenda offers a way forward in the advancement of inclusive citizenship for persons with dementia, as it entails a rethinking of the notion of (human) responsibility in civil society (Häkli 2018). According to Häkli, in a modern (digital) society it is important to understand how agency (understood as efficacy) is distributed among humans and non-humans; not only people (p.3). Recall, for example, how Bernard’s wife was reluctant to accept a GPS device for fear of it working *too* efficiently. As Jenkins (2017b) has pointed out: ‘if we are to realise fully the potential of 21st century technologies to promote social inclusion, there needs to be recognition that humanism is not the answer to all deficiencies in the care and treatment of people with neurocognitive impairments. Indeed, in some respects, humans and humanism are, themselves, part of the problem’ (p.497) – one only has to consider the discriminatory practices that many disabled people have to face (such as incarceration) to realise this (Goodley, Lawthom, and Liddiard, 2019). A post human agenda is a timely proposition, as we live in a world that is not only more digitalised, but also more aware of the benefits of animals (particularly dogs) for disabled people, including persons with dementia.

We know from recent thinking on social citizenship that ‘struggles over access to social rights, state resources and inclusion take different shapes’ (Yalçin-Heckmann 2011: 435). Based on the relationships described in this study, for persons with dementia those struggles are primarily cognitive in form; the processes and practices of provision, conditionality and membership (i.e. social citizenship) all require thought. Hence, access work is shared with not only non-humans, but also state agents (i.e. the police and NHS workers), public non-state actors (i.e. shopkeepers) and civil organisations such as the church. Italian sociologists describe this as a ‘circle of sharing’ and consider it a specific feature of the new civil society and public space (Giarelli & Spina, 2014: 245). From an inclusive citizenship perspective, such a circle is vital for enabling people with a dementia to access and mediate public spaces.

The nature of access work described in this study confirm findings from earlier studies involving persons with dementia, for example, the lack of advice and support in the process of accessing formal care services (Kerpershoek et al. 2016) and the challenges of grocery shopping when organisational skills are disrupted (Brorsson et al. 2014). Moreover, it shows how, like other research participants, persons with dementia in this study were trying to live in a ‘civil way, as good citizens’ (Stack 2012: 875). Think, for example, of how concerned Iain was about his tendency to forget whilst out shopping. This article makes an empirical and theoretical contribution to the existing literature by aligning these practices and processes to inclusive social citizenship, and in particular, the wider systemic shift to creating an inclusive citizenry.

Finally, our concerns as scholars are invariably theoretical and in reality, inconsequential when compared to the colossally complex challenges that citizens with dementia and their families have to face on a day to day basis. As this paper has shown, such challenges are likely to be practical (e.g. learning how to use technologies), moral (e.g. choosing how and when to curtail a person’s freedom), and neurological (e.g. living through altering cognitive capacities). Therefore, our primary responsibility should be to engage with those living with dementia to recognise these challenges and find solutions, so that inclusive (social) citizenship can be mediated in even more pluralistic ways in the years ahead.

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