## Scanning the Conceptual Horizons of Citizenship

Ruth Bartlett

Faculty of Health Sciences

University of Southampton

## Abstract

This paper scans recent developments within citizenship studies and relates them to the field of dementia, specifically the ‘dementia friendly communities’ (DFC) agenda. The DFC agenda is selected for several reasons, most notably because, it is an area of practice in the field of dementia where citizenship is perhaps most clearly enacted. The aim of the paper is to help with the advancement of social citizenship as a key concept for dementia studies, by using two of the latest ideas within citizenship studies; namely, understandings of citizenship as (1) occurring in ordinary places, and (2) potentially enacted within the domestic sphere to explore DFCs. It is argued that the interplay between these two developments pave the way for deeper consideration and realisation of social citizenship in the context of people with dementia.

## Introduction

Citizenship as a core consideration in understanding and responding to the experience of dementia has gained increasing currency over the past ten years. National pledges such as the Charter of Rights for People with Dementia and their Carers in Scotland, as well as a global policy emphasis on the full participation of people with dementia in society show how ideas associated with citizenship - such as inclusivity, recognition, and people enjoying rights – are becoming integral to dementia discourse (World HealthOrganisation, 2012). At the same time, scholars are increasingly using citizenship to challenge and advance dementia discourse. A general review of journal articles using both ‘citizenship’ and ‘dementia’ turned up over 80 references, almost all published since 2006.

The notion of citizenship has been picked up in a variety of ways. These include, for example, in relation to social work practice (Tanner, 2013); policy debates in Sweden (Nedlund & Nordh, 2015); long-term care (Brannelly, 2011); care encounters (Österholm & Hydén, 2014) and mental capacity legislation (Boyle, 2008). In each of these cases, scholars seek to make citizenship a meaningful proposition for advancing dementia care practice in some way.

Alongside the growing emphasis on citizenship within the dementia field, scholars of citizenship studies continue to push debates about the meaning and application of citizenship, especially within the context of ‘ordinary’ people who are not politically engaged, and within the domestic sphere – the home (e.g. Kershaw, 2010). These are promising developments within not only citizenship studies, but also, as I argue in this paper, for social researchers in the dementia field; not least because they help pave the way for enacting and advancing the social justice agenda in relation to people with dementia.

The purpose of this paper is to scan recent developments within citizenship studies and apply these to the field of dementia studies. The paper begins by noting the renewed interest in citizenship amongst social scientists, before outlining two specific developments within this field, namely, citizenship within the practice of ‘the ordinary’, and viewing care in the domestic sphere through a citizenship lens. These ideas are then applied to the DFC agenda, to extend understanding and help pave the way for fresh areas of research and practice to evolve.

## Conceptual developments within citizenship studies

Before outlining specific developments, it is important to note the renewed significance of citizenship in recent years. As one citizenship scholar notes, ‘the idea of citizenship has become more than a mere concept, it has become a meaningful and effective horizon for political imagination across the globe’ (Hansen, 2015: 229). There are, for example, a range of book titles published on the topic within the past five years: *The Ironies of Citizenship; Disputing Citizenship; Beyond Citizenship: Feminism and the Transformation of Belonging; Contours of Citizenship,* and the *Archaeology of Citizenship*. These assorted works show not only the continual appeal of citizenship but also how it is seen as in need of critical redefinition. As Hansen (2015: 231) goes onto suggest: ‘it is rarely clear what full citizenship entails and herein lies the protean force of the idea of citizenship; it is a never fully realised ideal that always has to be invoked, revisited and discursively reconstructed in order to be effective’. Thus, citizenship is both an elusive concept and ideal to strive for when seeking to improve society

Perhaps most significantly, it is possible to discern within citizenship studies a growing concern for people with disabilities (e.g. Emery, 2009, Guldvik, Askheim, & Johansen, 2013) and older people (Phelan, 2012). Such concerns recognize that there has been a tendency within both citizenship and disability studies to overlook older people, and instead focus on younger people and/or those with a physical disability(Jönson & Larsson, 2009). Certainly, older people with dementia are rarely mentioned within mainstream citizenship discourse. Concerns have also arisen because the traditional idea of citizenship has rested on ‘gendered dichotomies: between public and private, reason and emotion, the cognitive and embodied’ (Roseneil, 2013: 2). As a result, only certain people in certain places at certain times are bestowed citizenship - that is, those able to fulfil the rights and obligations laid down by the state, such as voting (Turner, 2007). So while the idea of citizenship is ‘intensely luring’, it is also inherently exclusive in its inclusionary promise (Roseneil, 2013). Hence, scholars are reworking citizenship with people with disabilities, older people, and other marginalised groups in mind. In particular, the following developments, question and extend the parameters of citizenship in a way that is highly pertinent for people with dementia.

### Citizenship within the practice of ‘ordinary’

One new development emerging from the field of citizenship is a move away from traditional notions of politics and perceptions of political participation to considering ‘ordinariness’ in citizenry terms (Neveu, 2015). Ordinary citizens –people who are not political – and ‘mundane spaces of daily sociability’, such as buses, parks, bars, and cafes, can be regarded as spaces of political potential because they provide opportunities for ‘subject positions to be experimented with and relations transformed’ (Neveu, 2015: 147). One can see the significance of this for the dementia field, as individuals with dementia become ‘fired up’ by perceived injustices. Take for example, Joy Watson – a woman diagnosed with Alzheimer’s disease on her 55th birthday. When Joy’s bank card got stuck in a cash machine at a petrol station, she went to get help from a member of staff, which a number of other customers waiting to pay took umbrage with because of the delay it caused. When she tried to explain she had dementia, they laughed at her. One customer continued to laugh at her as he followed her onto the forecourt. At which point Joy cried. Fortunately, another customer recognised Joy and showed understanding of her dementia (Alzheimer’s Society, 2015). Since then the community have got behind Joy and supported her campaigns for a ‘dementia haven’ where she lives. Such stories are important to not only narrate, but also to theorise through a citizenship lens so that they might restructure practice. Because ‘ordinary’ encounters like these between ‘ordinary people’ in ‘ordinary places’ can be politicising, in that they provide opportunities for the identification of struggle to emerge (Neveu, 2015). In the above case, it emboldened Joy to work harder for a fairer society.

### Citizenship within the domestic sphere

Another recent development within the field of citizenship studies is the idea that certain relational practices within the domestic sphere, such as caregiving, are best understood through a citizenship lens. Interpreting relationships in the domestic sphere in terms of political citizenship has long been a bone of contention for feminist scholars (Harrington-Meyer, Herd & Michel, 2000). Some hold the view that the essential meaning of citizenship is at risk of unravelling when applied to the domestic sphere (e.g. Lister, 2007); whereas others increasingly argue for its relevance to the home environment. Like, for example, in cases of domestic violence (García-Del Moral&Dersnah2014), or when caregiving is for identity – as is the case when caregivers lack the time or resources to support the care recipient’s language or faith-based needs (Kershaw, 2010). In these situations, scholars argue, the domestic sphere should be afforded the status of political citizenship. The point here is that citizenship practices are shaped by the ‘relational axes of inequality’…*within* the home, as well as outside (García-Del Moral & Dersnah: 662). Thus, the domestic contours of citizenship are as important to consider as the ‘public’ ones.

This seems an important consideration for dementia studies; given that individuals with dementia are at risk of micro injustices within the home. Such injustices may not be perceived as such, and they may be the only way a carer can cope when support services are lacking, nevertheless they act to curtail a person’s opportunities and freedoms. For example, some individuals report not going out as much because their families are anxious about them doing so, and without the ‘support of friends would be confined inside more often’(Brittain, Corner, Robinson, & Bond, 2010: 278). Clearly, the discourse of citizenship has bearing on these kinds of situations.

With few exceptions, injustices within the domestic sphere are rarely referred to in the context of citizenship and people with dementia (Boyle, 2013). Most of the 80 papers referred to in the introduction, are based on public service settings and/or focus on care dyads between service providers and families affected by dementia. There is an absence of discussion about the micro injustices faced by people with dementia within the home. Yet what happens inside and outside the home is inevitably intertwined and politicised for many people living with dementia. Take for example, the situation of one gentleman, caring for his wife (with dementia) who could be violent, he ‘found that neither his children, his General Practitioner nor his priest were prepared to acknowledge the situation in which he found himself after almost 60 years of marriage (Joseph Rowntree Foundation, 2012: 39). This gentleman faced interpersonal violence at home on his own, because his personal community could not recognise it as such or deal with it. It is quite possible that others face similar infringements to their identity and agency within their own homes. Indeed, work by Boyle (2013: 240) found that male carers are less likely to facilitate the autonomy of their partners (with dementia) than their female counterparts. Thus, the application of citizenship within the domestic sphere is an important consideration for dementia studies.

To summarise, there have been two recent developments within citizenship studies, which I believe hold the most promise and relevance for our field. They are about understanding citizenship as (1) occurring in ordinary places and (2) potentially enacted within the domestic sphere. They hold the most promise because they help pave the way to the implementation of citizenship, and it is this agenda we now turn. Specifically, I want to explore the relevance of these two ideas to the ‘dementia-friendly communities’ agenda as this is arguably the clearest opportunity for realising the citizenship of people with dementia. Moreover, the notion of a ‘dementia-friendly community’ is in its infancy and under theorised, and so the challenges of realising it have yet to be fully scoped or invoked.

## Using social citizenship to advance the ‘dementia-friendly communities’ (DFC) agenda

One area of practice where recent developments within citizenship studies can be used to advance our field, is the ‘dementia friendly communities’ (DFC) agenda. A DFC is defined as one in which ‘people with dementia are empowered to have high aspirations and feel confident, knowing that they can contribute and participate in activities that are meaningful to them (Alzheimer’s Society, 2013: viii). The DFC agenda is a relevant area of practice to focus upon for several reasons. Firstly, it has growing international appeal and currency. Initially originating in Japan there is now a global flurry of initiatives, especially in the UK, across Europe and in Canada and the USA(Alzheimer’s Disease International, 2014). In the USA, for example, researchers have created a Tool Kit to support communities in becoming dementia friendly that is used in 33 communities across Minnesota (Barclay, Barclay & Mastery, 2015). While in England, a national recognition process and code of practice for communities aiming to become ‘dementia friendly’ has been developed by the Alzheimer’s Society as part of the Prime Minister’s Challenge on Dementia (Alzheimer’s Society, 2013). Other areas, like Ireland, are using the idea to galvanise individuals and families living with dementia into community action (Haggarty, 2013). In effect, then, like citizenship, the idea of a DFC has also become a meaningful and effective horizon for political imagination across the globe.

A second reason why the DFC agenda is a relevant area to explore is because social citizenship, defined as a status, practice or relationship in which a person with dementia is free from discrimination and despair and has opportunities to grow, is at its core (Bartlett and O’Connor, 2010). Mitchell (2012: 1) draws attention to both the implicit and explicit citizenship underpinnings in relation to the DFC agenda:

‘the term ‘dementia friendly communities’ has emerged in recent years as policy makers and practitioners seek new ways to address the steady rise in numbers of people with dementia as the population ages. It reflects a growing movement to remind society that people with dementia have the same rights as everyone else to be treated with dignity and respect, to lead independent, autonomous lives and to continue to be active citizens in society whose opinions are heard and acted upon’.

This author draws attention to the link between ideas associated with citizenship, such as rights, agency, and participation. Others highlight the collective nature of the DFC agenda and suggest that the key to realising it is to build relationships in communities (e.g. Alzheimer’s Society, 2013). The initiative can thus be seen as a struggle for citizenship in that it represents an attempt to change neighbourhoods so that people with dementia are better understood, recognised, and situated as equal citizens.

A third reason for selecting DFCs is because the agenda is in its infancy, so the latest thinking within citizenship studies could be used to help shape its development. To date, most research related to DFCs has focused on the built environment. Evidence is therefore available about the design principles for a dementia-friendly community, such as visually attractive cues, contrast, and legibility, and the features of a dementia-friendly neighbourhood, such as short and narrow streets, and wide flat footpaths (Mitchell, 2012). Current work on dementia-friendly neighbourhoods aims to build on and advance this research by working closely with people with dementia, businesses and shops to generate even greater understanding and awareness. While such work is clearly important, the ‘relational axes of inequality’ or political struggles that people face, in ordinary spaces and in their own homes, like the ones in the examples above, remain somewhat neglected. Thus, it has been suggested that a more ‘political approach that seeks to expose discrimination’ is used to advance the DFC agenda (Wright, 2014 p. 283). In effect, a social citizenship approach, in which freedom from discrimination and despair, and opportunities to grow, are the desired outcomes.

A fourth reason for selecting the DFC agenda is because the places for exclusion and inclusion are still undefined or unfolding. The term ‘community’ in the discourse of ‘dementia-friendly communities’ is generally taken to mean public spaces such as cafes, shops and parks (Alzheimer’s Society, 2013). A focus on the outside environment has been well overdue, and so there has been a great deal of emphasis on this (Brittain et al, 2010). However, one of the goals of DFCs is to create a safe environment within the home and outside (Haggarty, 2013). So DFCs need not exclusively be about the external/public sphere. Given the latest thinking about the domestic spheres of citizenship, it might be timely for the DFC agenda to take what might be regarded as a ‘feminist turn’ into the home. Such a turn would involve exploring the relational links and gulfs between and within individuals and families, and the state and non-state actors, to gain a fuller sense of the injustices that people face within their communities.

The final reason why the DFC agenda has been selected is because the role of non-state actors and ‘ordinary’ citizens with dementia remains unclear. As is the case with most quests for citizenship, DFCs have tended to ‘emerge in complex interplays between state and non-state actors’ and so power struggles inevitably occur (de Koning, Jaffe, & Koster, 2015: 122). Take, for instance, how the DFC agenda has unfolded in England. Initially implemented by the Prime Minister’s Challenge in collaboration with the Alzheimer’s Society, it now involves other non-state actors, including the Joseph Rowntree Foundation (Alzheimer’s Society, 2013). Given that civil society is an arena for struggles between different groups and projects (Filc, 2014: 173), it is perhaps unsurprising that some people with dementia have reported to say that they do not want to be ‘taken over’ by the agendas of larger organisations (JRF, 2013); or can sometimes feel their involvement at a political level is tokenistic (Bartlett, 2014).

Elsewhere, in regions of the world where the state and non-state actors are less involved in implementing DFCs, the story is quite different. Ordinary citizens are clearly the instigators of change and ‘naturally occurring DFCs’ have occurred – as was the case in Tasmania when Gordon Nutt, who has dementia, took it upon himself (with his wife) to educate local shopkeepers about the needs and rights of people with dementia (Alzheimer’s Disease International, 2014). The point here is not to undermine the role of non-state actors in the DFCs agenda but to raise questions about their role, especially in regard to shaping the citizenship features, which has traditionally been the role of the state (de Koning et al., 2015). Moreover, it is about emphasising the importance of focusing on the ‘ordinary’ – the everyday problems that vex people with dementia and their families - rather than organisational agendas. It is only by working through the ‘ordinary’ that otherwise unseen barriers to participation and growth are rendered visible (Neveu, 2015).

## Conclusions

This paper makes a contribution to using citizenship as a core concept for dementia studies in two ways. First, by scanning recent developments within citizenship studies, it shows how interconnected many of the ideas are between these two fields. This suggests that dementia scholars might need to keep abreast of future developments within citizenship studies, and vice versa. Second, by using fresh ideas within citizenship studies to explore the DFC agenda, fruitful areas of thinking and practice have begun to emerge. These relate to the ordinary and domestic spheres of citizenship, and in particular, the value of exploring in/justices wherever they may occur.

As I have argued elsewhere, the struggle for citizenship has only just begun for people with dementia (Bartlett, 2014). It is a long-term, multifarious process, in which ‘ordinary’ citizens with dementia, as well as non-state actors, are still finding and framing their role. Critically, however, people with dementia are beginning to recognise that they have a right to demand equality and justice. Some, like Joy, are mobilising around more formal DFCs projects, whereas others, like Gordon are doing so independently of the state and non-state actors. Clearly, there are different ways of practicing and realising social citizenship. The struggle is thus a collective one, situated within a myriad of relationships that extend beyond dyadic relationships (Barnes, 2015). Indeed, it is a priority for everyone (Alzheimer’s Society, 2013).

Finally, while there has been considerable progress in terms of understanding and theorising dementia through a citizenship lens, such work is embryonic and more discursive analysis of practice and policy through a citizenship lens is required to help advance the social justice agenda in relation to people with dementia.

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