



Citizenship in action: the lived experiences of citizens with dementia who campaign for social change

Ruth Bartlett

To cite this article: Ruth Bartlett (2014) Citizenship in action: the lived experiences of citizens with dementia who campaign for social change, *Disability & Society*, 29:8, 1291-1304, DOI: [10.1080/09687599.2014.924905](https://doi.org/10.1080/09687599.2014.924905)

To link to this article: <https://doi.org/10.1080/09687599.2014.924905>



Published online: 29 Jul 2014.



Submit your article to this journal [↗](#)



Article views: 2174



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 25 View citing articles [↗](#)

Citizenship in action: the lived experiences of citizens with dementia who campaign for social change

Ruth Bartlett*

*Faculty of Health Sciences, Centre for Innovation and Leadership in Health Sciences,
University of Southampton, Southampton, UK*

(Received 9 August 2013; final version received 13 May 2014)

This article examines the experiences of citizens with dementia who campaign for social change, with a particular focus on the effects of campaigning on citizenry identity and psycho-emotional well-being. In diary-interviews, 16 people with dementia recorded and described their experiences of campaigning. Findings revealed that although campaigning can be energising and reaffirming of citizen identity, because it (re)located a person within the realm of work, individuals may experience dementia-related fatigue and oppression linked to normative expectations about what someone with dementia ‘should’ be like. The discussion is linked to critical debates within disability studies about the psycho-emotional aspects of impairment and disability, and concludes that the struggle for citizenship has only just begun for people with dementia.

Keywords: dementia; citizenship; campaigning; identity; psycho-emotional

Points of interest

- Campaigning for social change can be energising and reaffirming of citizen identity for individuals with dementia.
- Individuals may experience fatigue due to the dementia, and oppression linked to normative expectations about what someone with dementia ‘should’ be like.
- The ‘struggle for citizenship’ has only just begun for people with dementia.

Introduction

Enabling people with disabilities to participate in society as equal citizens is a long-standing theme within disability studies (for example, Barton 1993; Jayasooria 1999; Kjellberg 2002; Van-Houten and Bellemakers 2002). Citizenship is defined by disability scholars as a ‘process of proactive engagement’ in society in which ‘differentials of power’ are acknowledged and addressed (Beckett 2005, 405). While the idea of citizenship is extended to people with physical disabilities, and increasingly to those with learning disabilities (Kjellberg 2002; Redley 2009), there has been less application of citizenship in relation to people with dementia. The experiences of

*Email: R.L.Bartlett@soton.ac.uk

people with dementia are under-represented in disability studies, and individuals with this particular disability are typically positioned as passive recipients of welfare, rather than citizens (Bartlett and O'Conner 2010). Nevertheless, dementia is a disability as defined by the United Nations Convention on the Rights of Persons with Disabilities and so the issues facing those living with this impairment are essential to examine for a full debate about citizenship and people with a disability.

This article therefore examines the lived experiences of citizens with dementia who campaign for social change, in the context of critical debates about the psycho-emotional dimensions of disability (Thomas 1999). Discussion is based upon a qualitative study conducted in the United Kingdom (2008–2010), which aimed to explore peoples' motivations for campaigning and the impact of such practices on citizen identity and psycho-emotional well-being. The article begins by examining the notion of effective citizenship in the context of people with dementia, before describing the study design and reporting on findings germane to understanding the psycho-emotional aspects of disability as experienced by people with dementia. The overall aim of the paper is to inform and advance debate about the psycho-emotional dimensions of disability by highlighting the oppression and barriers experienced by citizens with dementia who campaign for social change.

Effective citizenship and people with dementia

Effective citizenship has been described as 'members of local communities being ready, willing, and able to get involved in local issues' and having the skills and knowledge to do so (Office of the Prime Minister 2006, 9). This view of citizenship emanates from the classic Aristotle notion of the 'good citizen' – that is, someone who is interested in civic life and politically active (Heater 1999). While it may be expedient for government to see citizenship in this way, a more nuanced and inclusive approach is required to ensure effective citizenship is meaningful in the context of people with a disability like dementia, who may not be willing or able to get involved. Disability scholars argue that for citizenship to be meaningful the voices of people with a disability must be central (Barton 1993, 236) and 'recognition' should be emphasised, as well as formal rights (Lister 2007, 51). In this way, individuals are intrinsically valued and regarded as (potentially) effective citizens, regardless of their actual capacity or willingness to participate.

An inclusive approach to citizenship is essential for individuals living with dementia, as dementia threatens one's identity and capacity to be an effective citizen in a socio-cultural and neurological sense. Socio-culturally, whichever form of dementia an individual has (e.g. Alzheimer's disease, Lewy Body dementia or vascular dementia), the diagnosis is often taken as evidence of an 'inability to participate as an agent within the civilised social world' (Gilleard and Higgs 2004, 169). For example, work by Behuniak (2011, 70) has shown how habitually people with dementia are linked to 'death', 'destruction', and 'zombies' – the living dead. Elsewhere she contends that the biomedical model of dementia reduces people with dementia to 'patients' and thus their 'potentialities' as citizens are denied (Behuniak 2010). Thus, people with dementia are not typically regarded as equal citizens, so strong is the biomedical lens (Beard and Neary 2013).

As well as attitudinal barriers, the nature of impairment caused by dementia places considerable demands on a person's capacity to realise their potential as a citizen. Dementia is a life-limiting condition, typically characterised by progressive

and significant changes to executive functions, including memory, language, reasoning, and thinking, as well as other adverse effects such as fatigue and visual-perceptual problems (Emery, Olga, and Thomas 2003) – all of the attributes that make us human and on which our ability to be an effective citizen depends. Thus, dementia offers an example of how biological factors inevitably entwine with societal factors when it comes to realising one's citizenry potential (Hughes 2009).

Despite these threats, there is evidence that individuals with dementia have the potential to continue being or becoming effective citizens. The policy emphasis on timely diagnosis means more and more people are in the early phases and able to live well with this condition (Department of Health 2012). At the same time, the social inclusion of people with dementia has become a global priority (World Health Organisation 2012) and support and opportunities for people with dementia to become spokespersons are increasing (Beard 2004a; Alzheimer's Disease International 2012a). Empirical work also shows that people can learn to 'resist and rework the negative cultural meaning of dementia' and find new meaning in their lives (MacRae 2008, 408). Others will 'employ the label dementia both as a resource and as a phenomenon that needs to be incorporated into their self-identity' (Beard and Fox 2008, 1509). Perhaps most significantly in the context of a discussion about effective citizenship, a diagnosis of dementia can 'serve as a catalyst for change' (Beard 2004b, 416); and can engender in some a 'fighting spirit' (Clare 2002). Like other people with disabilities, then, people with dementia are not a homogeneous group of 'passive patients' but a diverse group of men and women with a range of resources to draw upon.

The capacity of some people with dementia to resist negative stereotypes and be effective citizens is further evidenced by the significant minority of people with dementia in the United Kingdom and elsewhere becoming more influential in the public domain, speaking out, raising awareness, and participating in policy-making and implementation (hereon referred to as campaigning). Rather than passively accepting the tragic discourse of loss and demise typically associated with dementia, those directly affected by this condition are beginning to unite and seek opportunities to exert real influence in policy processes and society more generally (Clare, Rowlands, and Quin 2008; MacRae 2008; Bartlett 2014). For example, in recent years, user-led groups such as the Scottish Dementia Working Group have been established to influence public policy and attitudes (Weaks et al. 2012), and others have taken an active role in the work of Alzheimer's Associations (Beard 2004a), have educated healthcare students about the lived experience of dementia (Hope et al. 2007) and have become self-advocates (Knauss and Moyer 2006). In short, people with dementia are participating in their local communities, and the lens of citizenship is becoming increasingly apposite in the context of people with dementia (see, for example, Gilmour and Brannelly 2010; Bartlett and O'Conner 2010).

Despite the rise in campaigning amongst people with dementia, little is known about how such practices affect those involved, particularly in terms of citizen identity and psycho-emotional well-being. The limited evidence available suggests that people with dementia experience an increased sense of collective identity and confidence when they do unite and take action (Clare, Rowlands, and Quin 2008) and feel improvements in their health as a result (Whitfield 2006). However, these accounts were not interpreted from a critical disability perspective and the citizen identity of people with dementia remains under-theorised. Furthermore, questions remain about the psycho-emotional well-being of people with dementia who

campaign for social change. To what extent, for example, are people who campaign for social change hurt by negative stereotypes about dementia? And what are the personal costs of ‘coming out’ given the stigma that still surrounds dementia?

These questions are important to address for two broad reasons. First, from a demographic perspective it is imperative we know more about the lived experiences of people with dementia who campaign for social change, as numbers of people with this condition are growing. Recently, there were estimated to be 35.6 million people living with dementia worldwide, increasing to 65.7 million by 2030 and 115.4 million by 2050 (Alzheimer’s Disease International 2012b). Given this rising incidence and aforementioned policy trend in the United Kingdom and elsewhere on timely diagnosis, more and more (younger) people with dementia are likely to become involved in public life (Department of Health 2012). Indeed, one US policy-maker forecasts a ‘cohort effect’ and a greater number of self-advocates and campaigners in the years ahead (Beard 2004a, 811). It is important, therefore, to know more about this phenomenon so that the citizenry potential of this group of people with a disability is fully harnessed, and any oppressive practices are identified and avoided.

Second, research in cognate areas suggests that taking action can be empowering but it is not an unequivocal benefit. Health movement scholars have found, for example, that although intrinsically satisfying, getting involved in campaign work can be a struggle (Allsop, Jones, and Baggot 2004). In particular, older people and people with a disability may find community involvement activities tiring and onerous, especially when support requirements are not addressed or met (Attree et al. 2011). Others suggest that involvement in local issues can lead people with mental health problems to feel resentful about being co-opted into an ‘oppressive system’ (Wallcraft, Reid, and Sweeney 2003, 76) and undermined and ‘used’ by health professionals (Cotterell et al. 2011). Clearly the process of campaigning is a complex one, especially for people with a disability who may require support from non-disabled people and charitable organisations.

The research study

A two-year qualitative study of 16 people with dementia across the United Kingdom used the diary-interview method to elicit information on individual motivations for and experiences of taking action. A pre-diary interview was conducted with 16 individuals with dementia identified as campaigning for social change to some degree and in some way; for example, writing letters to local papers, speaking out in public, lobbying politicians, blogging, and chairing/attending campaign meetings. Individuals were excluded if there were concerns about their capacity to consent or physical health. With four exceptions, interviews were conducted on a one-to-one basis and in the person’s own home. A focus group was conducted in a meeting room with four participants affiliated to the same campaign group. This was followed by a diary-keeping phase. Participants were asked to keep a diary about their life as a ‘campaigner’ for one month. The traditional paper-based diary method was modified to include photographic and audio diaries to enable participation and to gain a more dynamic understanding of the topic. Five participants kept a photographic diary, three kept a written diary, one kept an audio diary, and the remaining seven participants kept a combination of one or more of the diary methods but no one chose to keep all three. While participants were keeping their diary, the research team spent

approximately 30 hours participating in and observing key events that participants were involved in, including an Annual General Meeting and national conference. The third phase consisted of a post-diary interview. With one exception these were conducted face to face in an appropriate place in or near the person's home or campaign base. A telephone interview was conducted with one participant due to time constraints. Post-diary interviews provided an opportunity to explore and expand upon diary entries and to explore in more depth people's experiences of taking action. A more detailed discussion of using the diary-interview method to research the lives of people with dementia is reported elsewhere (Bartlett 2012).

Data were handled manually using a combination of content and thematic analysis techniques and coding and interpretive techniques (Richards 2005). Interview data were coded and catalogued using basic search and categorisation macros adapted by my research assistant. At the same time, diaries were examined for content and data pertinent to the study were word-processed and coded. Photographic images were classified according to the meaning ascribed to them by both the participant and researcher. The process involved sorting images according to content (such as family members, forms of transport, people) to establish what is given salience and what is not. Then, we examined the meanings participants had invested in these images and compared these with our own. These stages of analysis allowed us to understand the spoken narrative in the context of visual images, which added meaning to and strengthened a person's stories (Pink 2009).

Having coded the dataset, with research assistance I examined how categories related to each other and constructed core themes to explain the link. Wherever possible, themes were constructed using the words of the participants. In developing this paper, I drew upon Goffman's dramaturgical ideas concerning 'impression management' to inform the interpretation of peoples' accounts of campaigning (Goffman 1959). The process of knowing ourselves, of forming and reforming identities, is a constant one played out in public and private areas of our everyday life – or, in Goffman's terms, in 'front regions' and 'back regions' (Goffman 1959). These ideas were helpful when analysing personal diary data, interviews, and the actions of people who campaign for social change, as they provide a structure for understanding the synergy between public and private lives. Furthermore, as will become evident, the discussion of 'back stage' mirrors similar discussions and tensions with the wider disability movement concerning the participation of people with hidden impairments.

Ethical issues

Formal ethical approval for the study was obtained from a university ethics committee. Researchers met with potential participants to gain informed consent in the person's own home or campaign office. Informed consent was gained in writing from participants after talking to them about the study and explaining how the information will be used. The process of gaining informed consent was formally repeated at the start of each phase of data collection, giving participants several opportunities to leave the study and the researcher a chance to reassess capacity.

When presenting research findings it is usual practice for researchers to anonymise data in order to protect the identity of participants. However, in the context of this study, as explained elsewhere, for most participants being identified was an integral part of taking action, and so those who waived their right to use pseudonym are

identified and given a voice (Bartlett 2014). The identity of two participants has been protected (at their request) and the pseudonym they asked us to use will be used to distinguish their data. In doing this it is acknowledged that individuals have a right to publicity as well as anonymity (Bauman 1999). That said, I have followed the advice of Hammersley and Atkinson (2007) and sought to refrain from publishing anything which may cause embarrassment or distress to those affected; hence, the source of some data is not stated.

Results

The participants were 11 men and five women, aged 53–74 years (mean 64 years). All were of white British origin. People told us that they had had a diagnosis of dementia for varying periods of time, most ranging from between two and 11 years. Twelve had some previous experience of taking action and had worked in professional or managerial roles, while the remainder had never taken action or campaigned before and had worked in the trade sector or public service. Previous campaign issues ranged between trade union matters and ‘compassion on world farming’ to anti-Genetically Modified foods and animal rights.

Working to exert influence – ‘front stage’

Modern notions of citizenship are constructed around work and ‘doing’ (Isin and Turner 2007). It was significant, then, to find that taking action was conceptualised by most participants as work; some participants explicitly used the lexicon of work in their verbal accounts of campaigning. For example: ‘[taking action] is keeping me interested and keeping me *working*’ (Trevor), and Graham perceived the forty events he had been involved in the previous year as ‘just another days *work*’ (emphasis added). A few individuals compared their current role with their pre-dementia working role, and considered what they were doing now to be more rewarding. Take, for example, this comment from James: ‘it’s a sense of self satisfaction. When I worked (in finance) I didn’t get very good reviews, and it’s nice to be able to do things and people say to you, “you’ve done well”. It’s a sense of recognition’. Likewise, Ross said how an email from someone, thanking him for his talk, ‘makes it all worthwhile’. These data show how campaigning (re)located a person within the realm of work; thus participants were being citizens in the traditional sense of the term (Lister 2000).

Some activities were experienced as ‘hard work’, either because of the audience or the preparation involved. For example, reflecting on a photograph he had taken of himself talking to a group of medical students, Ross commented on how tough he found the session. He said: ‘we’ve done first year students, but third year medical students, that was the hardest’; asked what made it so hard, he said ‘it’s the way they fire back – they had the knowledge’. Ross, who was a retired painter and decorator, was not used to ‘knowledge-based work’. Similarly, another participant, when referring to her preparations for speaking to a younger audience, reported finding the work pleasurable but demanding. She said: ‘I enjoy preparing this type of lecture though the varieties of audience sometimes present a challenge’. These comments illustrate the challenges involved in being an effective citizen when you have dementia and/or are not used to participating in the way that is required.

During pre-diary interviews, participants were asked whether they were paid for what they did and whether they thought they should be. Responses to both questions were mixed. Participants who accepted payment did so in the context of specific activities. For example, Graham recognised that some organisations would pay him: 'I do get a reimbursement from the NHS they pay me for every meeting I go to'. James, on the other hand, told people: 'if you want to pay me for [talks], just pay it into [the group's] funds'. Being part of a campaign group relinquished him from the responsibility of accepting payment. Another participant wanted to make it clear that although the experience felt like work, he was not motivated by money. He said: 'I might spend 2 hours getting there, an hour talking and an hour and a half getting back. For 15 pound, less – so it comes out about 12 pound. 12 pound for nearly a day's work. It's not financial'. This confirms, once again, how taking action relocated participants within the realm of work.

The effects of working without material reward may be demoralising and outweigh any benefits to a person's mental health (Schneider 1998). One participant revealed in her pre-diary interview how adversely not being paid affected her. She said: 'sometimes you feel (course instructors) are using you. They're getting paid and they're giving you buttons. And at times I do feel abused'. Similarly, another participant felt quite strongly that as she was engaged in the same activities as salaried professionals, she should also be paid. This is what she said in relation to her first (unpaid) experience of speaking at a conference: 'the first one I did – I thought blow this, I should get a fee', which she requested and now receives. The indignity of working but not being paid was untenable for this participant.

Other participants said they did not receive payment and preferred it that way, partly because they thought it might adversely affect the nature of their relationship with professionals. Dennis, for example, when speaking about his involvement on a 'Service User and Carer Partnership Forum', said:

the advantage I've got – with being a patient – you can say what you think and it doesn't matter does it because they can't do anything to you. They can't sack me can they, you see, you're not working for anybody.

Self-identifying as a patient, a 'citizen patient' – that is, someone who gets involved in health services (Hughes 2009) – was advantageous as far as this participant was concerned.

Dealing with the effects of dementia – 'back stage'

Dealing with the effects of dementia was a central topic in participants' accounts. In interviews, some people referred to it as a struggle or frustration that went unseen: 'the biggest problem is when you say to someone I've got dementia and they say you're okay, you're bright. We look okay, but nobody sees beyond what it takes to get up in the morning, what effort it takes'. Likewise, another male participant said how slowly he worked because of his dementia. He said: 'I was still preparing all my papers at gone 1 am; everything takes me such a long time. I have to go over each step to check for mistakes'. These data highlight how the effort required to be an effective citizen often goes unseen by professionals.

Photographic diaries elicited further information about how people experienced the effects of dementia 'back-stage'. For example, Dennis submitted an image of himself lying on his sofa at home, eyes half-closed and arms folded, which he said

his wife had taken to show how tired he got, and Daphne took a photograph of herself sitting in a chair of an Alzheimer's Society branch with eyes closed to relay the fatigue she experienced. These visual data provided an important route into an otherwise hidden aspect of campaigning, namely needing time to rest and re-charge.

For most participants, one of the most troublesome effects of dementia was exhaustion. As Edward said:

part of the problem with dementia is you don't sleep (and so) you're desperately tired, you want to rest, you want to close your eyes and switch off, and you can't always do that ... so you just try and put on the best show you can.

Similarly, Tony associated his tiredness with the dementia, he said: 'I tire more quickly now and that's partly the disorder'. Having to campaign with dementia fatigue was commented upon by several participants: 'My biggest challenge really is keeping effective without total exhaustion'; and another participant said, 'I am performing in whatever way I need to perform and I come back on the train and I am exhausted for the next couple of days'. The phraseology of 'putting on a show' and 'performing' in the above quotes reveals how participants sometimes felt duty-bound to campaign, even though they felt differently inside. A point I will return to later.

Several participants spoke about the psycho-emotional consequences of taking action, which also went unseen in public. For example, one participant, who from observations seemed to be in full control of her emotions, spoke in her post-diary interview of an inner turmoil that outsiders did not see. She said: 'Sometimes the heartbreak and emotions that come with it, nobody sees that, and sometimes it's frustrating to see that nobody takes it into consideration'. Similarly, Ross revealed in his pre-diary interview how, after giving a talk to a group of 30 students, he let his guard down. He said: 'I was out having a smoke in the break and they all came out and started to ask me questions. I got a wee bit emotional there'. Sometimes the 'front stage' and backstage', which Goffman (1959) refers to, merge, making it difficult for a person to continue to maintain a 'social front'. Such data show how campaigners are not immune to feeling hurt, and therefore reconfirm the importance of taking the experiential dimensions of disability into account (Reeve 2002).

Other participants referred to some of the practical problems created by their dementia, including, for example, forgetting to claim expenses. As Agnes said: 'I always say to (our administrator), will you do the thing with the expenses, because you know me ... I'd forgotten the other day and I was supposed to put it in'. Similarly, Daphne spoke of the challenges she experienced in processing expenses because of the dementia. She said: 'when you get a whole lot [of expenses] in a week from different bodies and you haven't got the forms it all gets a bit complicated'. Another participant spoke of the 'terror of forgetting stuff' whenever he was asked to speak in public. Standard administrative processes and social conventions can be an additional pressure, then, for those already dealing with cognitive changes associated with dementia.

A 'high price to pay'

Previous discussion highlighted how getting involved in local issues – being an effective citizen – can be empowering, but it is not an unequivocal benefit, particularly for individuals with a disability. In the context of this study, a number of

participants spoke about how there was, to use Edward's phrase, a 'high price to pay – he said: 'you just cannot keep using up what energy you have and not pay a price for it'. As well as feeling exhausted, some participants paid a 'high price' psycho-emotionally – that is, they felt bad inside. These accounts were often imbued with normative expectations about what someone with dementia 'should' be like. One participant, for example, described feeling awkward about being able to function so well. She said: 'I've had so many positive feedbacks that it almost makes me feel guilty in a way – it's a bit like survivors guilt'. Peter encountered a similar problem (although he sounded more angry than guilty about it):

some may argue that because I behave in the way I behave I can't possibly have (Lewy body dementia), but I must assure you that six months ago I went back for another scan and that it confirmed, that I do.

These data were interpreted to mean that so strong is the stereotype that people with dementia are 'totally confused' that anyone (with dementia) who does not present themselves in this way may feel or be considered a 'fraud'.

During the interviews, several study participants reported finding themselves caught between their identity as a person with dementia and their identity as an effective citizen. As one study participant said: 'the first barrier you meet is that people don't believe that you can have dementia if you can still function'. Another participant said that he had been asked 'are you sure you've got dementia?' (presumably because he was such an effective communicator) and Dennis recalled being quizzed (in a light-hearted way) by two care workers when he was with a support worker about 'which one' had dementia. He said it really 'puzzled them'. As such, these stories show how strong the association is between dementia and demise, and the degree to which someone with early dementia may have their 'illness credentials' questioned in the process of realising their potential as an active citizen.

The way we present ourselves publically may not reflect the way we feel inside (Goffman 1959). In this study, it was apparent that a few individuals engaged in emotional labour – that is, they put on a 'smile' to conceal how they truly felt (Hochschild 1983). For example, during the focus group interview, one participant remarked how the process of trying to bring about change could be a frustrating one. Hence, she said she told herself: 'keep your focus, keep it under control, small amounts, and do it with a smile on your face'. Another participant reported feeling the pressure to 'perform' even though he did not always feel like it. He said: 'you might not feel like speaking to a huge number of people but they're waiting to hear from you, and you have a duty or something'. These data and the phraseology of 'putting on a show' and 'performing' in earlier quotes suggest that participants were influenced by a duty-bound notion of citizenship – that is, they felt obligated to carry out certain tasks (such as public speaking) even though they may not have felt like doing so.

A few participants expressed regret about their loss of anonymity. Very high-profile participants acquired a kind of 'celebrity status', making it difficult for them and others to distinguish between their individual and collective selves. The effect of this on emotional well-being is best exemplified in a comment made by Agnes, who said: 'once you give you story over to a campaign and your face with it, you then pay a bigger price, me'. Elsewhere she mused about wanting the 'old Agnes back' – not the 'pre-diagnosis Agnes' but the 'pre-public figure Agnes'. These key quotes show how profoundly one's identity can be affected by taking part in high-profile

campaign work. Nevertheless, it is not something people are necessarily prepared for; one male participant remarked how he ‘sent him cold’ when he saw his face on the Internet, as if something had changed that could never be undone. These data show how campaigning can create a sense of loss for one’s former self.

Feeling pressurised to participate is regarded by some as one of the main problems with mainstream notions of citizenship; marginalised groups (such as people with dementia) may be ‘included in certain areas of social politics while being excluded in others’ (Ellison 2000, 8.2). In this study, two female participants made comments that suggested they felt exploited by more powerful organisations. For example, one woman said in relation to her charity work: ‘I feel like others that we are “wheeled out” when needed’, as if she has no control over what she does or where she goes. Additionally, in her diary, she wrote ‘we are NOT going to be tick boxes!’ – emphasising (through capitalisation and punctuation) her rejection of a tokenistic identity. Another woman reported doubts about the impact she was having, writing in her diary: ‘I am wondering if all this taking action is of any use and if I am only being used (by the media)’. While these views were not widespread, the fact that they were voiced by two women highlights how the experience of campaigning can be compounded by gender factors, and may lead to feelings of anger and discontent.

Discussion and conclusions

In this paper, the lived experiences of men and women with dementia who campaign for social change have been explored, with a particular focus on how such experiences affect citizen identity and psycho-emotional well-being. It has been shown how campaigning can be energising and reaffirming of citizen identity because it (re)locates a person within the realm of work; however, individuals may experience fatigue due to their dementia and oppression linked to normative expectations about what someone with dementia ‘should’ be like. As such, the paper contributes to critical discussion within disability studies about the ‘psycho-emotional dimensions of disability.

According to Thomas (1999, 56) the ‘psycho-emotional dimensions of disablism are closely bound up with socio-cultural processes which generate negative attitudes about impairment and disability, and sustain prejudicial meanings, ideas, discourses and, images and stereotypes’. Unlike impairment effects, then, (like fatigue) the psycho-emotional dimensions have a social origin (Thomas 2007). This study has begun to reveal the way these manifest for people with dementia, such as, for example, feeling guilty for not being ‘more impaired’, having one’s dementia identity questioned by those without dementia, and feeling ‘terrified’ about forgetting stuff. Such experiences are attributable to negative stereotypes about dementia, rather than the condition itself. Or, as is the case with forgetting, they represent an example of a corporal experience that is feared, ignored, despised, and rejected (Wendall 1996, 85). Thus, they add weight to the view that emotional oppression can be as disabling as physical and structural barriers (Reeve 2002).

Central to these accounts of campaigning were cultural markers associated with dementia. None of the study participants behaved in a way that one might ‘expect’ a person with dementia to behave and virtually all had the authenticity of their illness identity questioned. As Charmaz (1991, 100) points out, it is difficult for individuals to ‘enforce their identity claim as ill’ as long as they appear healthy, articulate, and

competent. Other researchers have found a ‘conflict between living positively with dementia and enduring negative attitudes’ (O’Sullivan, Hocking, and Spence 2013, 1) and argue that people with dementia have to deal with internal and external threats to their identity (Beard 2004b, 417). Negative attitudes are clearly a barrier, then, to being an effective citizen with dementia, which may help to explain why more people with dementia do not get involved in campaign work.

Earlier in this paper it was suggested that ‘recognition’ is an important aspect of ‘inclusive citizenship’ (Lister 2007, 50) – that is, ‘recognition and respect for differences’ – in this case, differences in a person’s lived experience of and response to dementia. Given the accounts of incredulity reported here, and the relatively small number of people with dementia who campaign for social change, the study raises important questions about what effective citizenship means for other people with dementia who are unable to contribute in this way. As one high-profile campaigner said: ‘I’ve been privileged in that I’ve been accepted. But the generality is once you get this diagnosis everybody suddenly puts you in a box somewhere down there’. This participant recognised that ‘there is status in being called (or seen as) an activist’ (Martin 2007, 22), because people usually experience a loss of status on being diagnosed with dementia (Langdon, Eagle, and Warner 2007). Therefore, I would suggest that people with dementia have only just begun their ‘struggle for citizenship’ and could learn a great deal from the insights of the disability movement (Barton 1993, 235).

One insight is that the psycho-emotional issues identified in the study arose not necessarily because participants were impaired, but because the deeper texts that underpin involvement were ‘informed and coded by non-impaired carnality’ (Paterson and Hughes 1999, 607). That is to say, the social rules which participants felt they had to abide by (such as public-speaking) were not rules that people with ‘carnal knowledge’ of dementia helped to create. As Paterson and Hughes (1999, 607) explain: ‘The scripts from which non-disabled people judge and bestow “social competence” are not scripts which people with an impairment have constructed’. Further work is needed by user-led organisations (like the Scottish Dementia Working Group) on developing ‘rules’ for campaigning which are not cranially biased and which allow people with this condition to be themselves.

Study findings should be considered alongside the limitations of the study. This was a comparatively small-scale study and there was less variation in the sample than was hoped for. Plus, the sample consisted of just one group – namely, relatively young, healthy people with dementia. The perspectives of older, more severely impaired people with dementia, family members, and professionals were not actively sought.

Nevertheless, the people with dementia involved in this study have refreshingly different stories to tell; stories that can help existing and future generations of people with dementia. As Richardson (1997, 58) explains: ‘collective stories that are based in the lived experience of people and deviate from the cultural story, provide new narratives; hearing them helps individuals to report their lives’. Not only are they ensuring the next generation of people diagnosed with dementia have more nuanced stories and cultural resources from which to draw, as a social group their actions and visibility in the public sphere constitute a counter-movement to the pathologising and paternalistic culture of previous decades.

Acknowledgements

The author would like to thank all of the individuals and organisations involved in this study, Dr John Chatwin and Dr E. J. Milne for research assistance, Prof. Catherine Pope and Mr Larry Gardiner for their encouragement and helpful comments on an earlier version of this paper, and two anonymous reviewers for comments.

Funding

The study was funded by the Economic and Social Research Council First Grant Scheme.

References

- Allsop, J., K. Jones, and R. Baggott. 2004. "Health Consumer Groups in the UK: A New Social Movement?" *Sociology of Health and Illness* 26 (6): 737–756.
- Alzheimer's Disease International. 2012a. *How to Successfully Involve People with Dementia in Speaking Roles for Organisations*. London: Alzheimer's Disease International.
- Alzheimer's Disease International. 2012b. *The World Alzheimer Report*. London: Alzheimer's Disease International.
- Attree, P., S. Morris, S. Payne, S. Vaughan, and S. Hinder. 2011. "Exploring the Influence of Service User Involvement on Health and Social Care Services for Cancer." *Health Expectations* 14 (1): 48–58.
- Barton, L. 1993. "The Struggle for Citizenship: The Case of Disabled People." *Disability, Handicap & Society* 8 (3): 235–248.
- Bauman, Z. 1999. *In Search of Politics*. Oxford: Polity.
- Bartlett, R. 2014. "The Emergent Modes of Dementia Activism." *Ageing & Society*. 34 (4): 623–644.
- Bartlett, R. 2012. "Modifying the Diary Interview Method to Research the Lives of People with Dementia." *Qualitative Health Research* 22 (12): 1717–1726.
- Bartlett, R., and D. O'Connor. 2010. *Broadening the Dementia Debate: Toward Social Citizenship*. Bristol: Policy Press.
- Beard, R. 2004a. "Advocating Voice: Organisational, Historical and Social Milieux of the Alzheimer's Disease Movement." *Sociology of Health and Illness* 26 (6): 797–819.
- Beard, R. 2004b. "In Their Voices: Identity Preservation and Experiences of Alzheimer's Disease." *Journal of Aging Studies* 18: 415–428.
- Beard, R., and P. Fox. 2008. "Resisting Social Disenfranchisement: Negotiating Collective Identities and Everyday Life with Dementia." *Social Science and Medicine* 66 (7): 1509–1520.
- Beard, R., and T. Neary. 2013. "Making Sense of Nonsense: Experiences of Mild Cognitive Impairment." *Sociology of Health and Illness* 35 (1): 130–146.
- Beckett, A. 2005. "Reconsidering Citizenship in the Light of the Concerns of the UK Disability Movement." *Citizenship Studies* 9 (4): 405–421.
- Behuniak, S. 2010. "Toward a Political Model of Dementia: Power as Compassionate Care." *Journal of Aging Studies* 24 (4): 231–240.
- Behuniak, S. 2011. "The Living Dead? The Construction of People with Dementia as Zombies." *Ageing & Society* 31: 70–92.
- Charmaz, K. 1991. *Good Days and Bad Days: The Self in Chronic Illness*. New Brunswick, NJ: Rutgers University Press.
- Clare, L. 2002. "We'll Fight It as Long as We Can: Coping with the Onset of Alzheimer's Disease." *Ageing and Mental Health* 6 (2): 139–148.
- Clare, L., J. Rowlands, and R. Quin. 2008. "Collective Strength: The Impact of Developing a Shared Social Identity in Early-stage Dementia." *Dementia: The International Journal of Social Research and Practice* 7: 9–30.
- Cotterell, P., G. Harlow, C. Morris, P. Beresford, B. Hanley, A. Sargeant, J. Sitzia, and K. Staley. 2011. "Service User Involvement in Cancer Care." *Health Expectations* 14 (2): 159–169.

- Department of Health. 2012. *The Prime Minister's Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015: A Report on Progress*. London: Stationary Office.
- Ellison, N. 2000. "Proactive and Defensive Engagement: Social Citizenship in a Changing Public Sphere." *Sociological Research Online* 5: 3.
- Emery, V., B. Olga, and T. Oxman. 2003. *Dementia: Presentations, Differential Diagnosis and Nosology*. Baltimore, MD: John Hopkins University Press.
- Gilleard, C., and P. Higgs. 2004. *Cultures of Ageing: Self, Citizen and the Body*. Harlow: Pearson Education Limited.
- Gilmour, J., and T. Brannely. 2010. "Representations of People with Dementia – Subaltern, Person, Citizen." *Nursing Inquiry* 17 (3): 240–247.
- Goffman, E. 1959. *The Presentation of Self*. London: Penguin Books.
- Hammersley, M., and P. Atkinson. 2007. *Ethnography: Principles and Practice*. 3rd ed. London: Routledge.
- Heater, D. 1999. *What is Citizenship?* Malden: Blackwell Publishers.
- Hochschild, A. 1983. *The Managed Heart: Commercialization of Human Feeling*. Berkeley: University of California Press.
- Hope, K., D. Pulsford, R. Thompson, A. Capstick, and T. Heyward. 2007. "Hearing the Voice of People with Dementia in Professional Education." *Nurse Education Today* 27: 821–824.
- Hughes, B. 2009. "Disability Activisms: Social Model Stalwarts and Biological Citizens." *Disability & Society* 24 (6): 677–688.
- Isin, E., and B. Turner. 2007. "Investigating Citizenship: An Agenda for Citizenship Studies." *Citizenship Studies* 11 (1): 5–17.
- Jayasooria, D. 1999. "Disabled People: Active or Passive Citizens – Reflections for the Malaysian Experience." *Disability & Society* 14 (3): 341–352.
- Kjellberg, A. 2002. "Being a Citizen." *Disability & Society* 17 (2): 187–203.
- Knauss, J., and D. Moyer. 2006. "The Role of Advocacy in Our Adventure with Alzheimer's." *Dementia: The International Journal of Social Research and Practice* 5: 67–71.
- Langdon, S., A. Eagle, and J. Warner. 2007. "Making Sense of Dementia in the Social World: A Qualitative Study." *Social Science and Medicine* 64 (4): 989–1000.
- Lister, R. 2000. "Strategies for Social Inclusion: Promoting Social Cohesion or Social Justice." In *Social Inclusion: Possibilities and Tensions*, edited by A. Stewart and P. Askonas, 37–54. Basingstoke: Palgrave MacMillan.
- Lister, R. 2007. "Inclusive Citizenship: Realizing the Potential." *Citizenship Studies* 11 (1): 49–61.
- MacRae, H. 2008. "Making the Best You Can of It': Living with Early-Stage Alzheimer's Disease." *Sociology of Health and Illness* 30 (3): 396–412.
- Martin, B. 2007. "Activism, Social and Political." In *(2007) Encyclopaedia of Activism and Social Justice*. vol. 1, edited by G. Anderson and K. Herr, 19–27. Thousand Oaks: Sage.
- Office of the Prime Minister. 2006. *Promoting Effective Citizenship and Community Empowerment: A Guide for Local Authorities on Enhancing Capacity and Public Participation*. London: Office of the Prime Minister.
- O'Sullivan, G., C. Hocking, and D. Spence. 2013. "Dementia: The Need for Attitudinal Change." *Dementia: The International Journal of Social Research and Practice* 13 (1): 1–15.
- Paterson, K., and B. Hughes. 1999. "Disability Studies and Phenomenology: The Carnal Politics of Everyday Life." *Disability & Society* 14 (5): 597–610.
- Pink, S. 2009. *Doing Sensory Ethnography*. London: Sage.
- Redley, M. 2009. "Understanding the Social Exclusion and Stalled Welfare of Citizens with Learning Disabilities." *Disability & Society* 24 (4): 489–501.
- Reeve, D. 2002. "Negotiating Psycho-emotional Dimensions of Disability and Their Influence on Identity Constructions." *Disability & Society* 17 (5): 493–508.
- Richards, L. 2005. *Handling Qualitative Data: A Practical Guide*. London: Sage.
- Richardson, L. 1997. *Fields of Play: Constructing an Academic Life: New Brunswick*. New Brunswick, NJ: Rutgers University Press.
- Schneider, J. 1998. "Work Interventions in Mental Health Care: Some Arguments and Recent Evidence." *Journal of Mental Health* 7 (1): 81–94.

- Thomas, C. 1999. *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.
- Thomas, C. 2007. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. New York: Palgrave Macmillan.
- Van Houten, D., and C. Bellemakers. 2002. "Equal Citizenship for All. Disability Policies in the Netherlands: Empowerment of Marginals." *Disability & Society* 17 (2): 171–185.
- Wallcraft, J., Rose J. Reid, and A. Sweeney. 2003. *On Our Own Terms: Users and Survivors of Mental Health Services Working Together for Support and Change*. Unpublished Report. Sainsbury Centre for Mental Health: London.
- Weaks, D., H. Wilkinson, A. Houston, and J. McKillop. 2012. *Perspectives on Ageing and Dementia*. York: Joseph Rowntree Foundation.
- Wendall, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.
- Whitfield, K. 2006. "Inclusivity and Dementia: Health Services Planning with Individuals with Dementia." *HealthCare Policy* 1 (2): 121–134.
- World Health Organisation. 2012. *Dementia: A Public Health Priority*. Geneva: World Health Organisation.