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From personhood to citizenship: Broadening the lens for dementia practice and research

Ruth Bartlett^{a,*}, Deborah O'Connor^{b,c,1}

^a *Bradford Dementia Group, Division of Dementia Studies, School of Health Studies, University of Bradford, Trinity Road, Bradford, BD5 0BP, UK*

^b *Centre for Research on Personhood in Dementia, University of British Columbia, 2080 West Mall, Vancouver, BC, Canada V6T 1Z2*

^c *School of Social Work and Family Studies, University of British Columbia, 2080 West Mall, Vancouver, BC, Canada V6T 1Z2*

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Abstract

Personhood has provided a lens for conceptualising dementia practice and research for over ten years. It has afforded the rationale and language for improving care and for raising consciousness about the status of people with dementia, as people, intrinsically worthy of respect. However, because personhood is essentially an apolitical concept concerned with psychosocial issues it may be too limiting. Citizenship provides another possible lens. Citizenship is used in cognate disciplines to promote the status of discriminated groups of people still further, to that of a person with power entitled to the same from life as everyone else. However, as citizenship tends to assume the self-cognizance to exercise rights and responsibilities, it may not be as appropriate for people with severe dementia. Both concepts are problematic then, taking too narrow a view of the human experience. For this field to develop over the next ten years it clearly needs a wider lens that is both inclusive of personhood and citizenship, but which also recognizes the complexities of human experience. This article reviews the relevance of personhood and citizenship for dementia practice and research, and argues for a broader lens that incorporates citizenship and sociological ideas about agency and structure. © 2006 Elsevier Inc. All rights reserved.

Keywords: Agency; Citizenship; Dementia; Personhood; Structure

1. Introduction

The field of dementia practice and research is changing. It is changing demographically as numbers of people with dementia in need of health and social care continue to grow. It is estimated that there are currently about 18 million people worldwide with Alzheimer's disease alone — a figure expected to nearly double by 2025 to 37 million ([World Health Organization, 2006](#)). The field is changing linguistically as the words and phrases used to describe people with dementia evolve. Until only recently, expressions such as 'the confused' ([Meacher, 1972](#)) and 'dementia sufferers' ([Cheston & Bender, 1999](#); [Jacques, 1992](#)) were commonly used. Now, people with dementia are more likely to be

* Corresponding author. Tel.: +44 1274 236468; fax: +44 1274 236395.

E-mail addresses: r.l.bartlett@bradford.ac.uk (R. Bartlett), deborah.oconnor@ubc.ca (D. O'Connor).

¹ Tel.: +1 604 822 5299.

referred to as ‘people with dementia’. In time, this may change. The field is changing as knowledge of effective treatments increases. For example, medications appear which promise to delay the onset of symptoms, and cognitive rehabilitation techniques are being developed allowing persons with dementia to assume more active involvement in decisions about their care and life generally (Clare, Wilson, Breen, & Hodges, 1999; Woods, 1996). These changes are giving rise to more searching questions about the experiences of people with dementia. In particular, the extent to which people with this condition experience discrimination is generating increasing scrutiny.

Older people with dementia are discriminated against at different levels and in different ways. On a macro level, discrimination can structure distress, disability and economic losses (Graham et al., 2003) making it difficult for people to access health services and enjoy community activities (DoH, 2004). It disadvantages communities in general by limiting the contributions of a particular group of people. On a micro level, it can lead people with dementia to feel stigmatised and less worthy (Gillies, 2000; Lyman, 1998), and to be seen and treated by care workers and others as less than human (Kitwood, 1997a). The main effect of discrimination against people with dementia at whatever level is that it compounds the neurological related problems a person already has and reduces opportunities for self expression and growth (Woods, 2001). It is for these reasons that discrimination is recognized as a public health issue (Link & Phelen, 2006).

One way in which discrimination is tackled in dementia practice and research is conceptually, on the basis of personhood. The personhood lens has done much to challenge the stigma and discrimination associated with dementia. It has provided a framework and language for raising consciousness about the status of people, as people, intrinsically worthy of respect and shifted understanding of dementia from a ‘technical (medical) framework’ to a humanistic perspective (Kitwood, 1993: 100). The lens of personhood has arguably become one of the most influential for dementia practice and research in the last decade (Brooker, 2004; Woods, 2001). However, while the strengths of personhood are widely recognised, the limitations of this lens are not. The first goal of this article therefore is to review the contribution, a focus on personhood has made to dementia practice and research, while also examining the boundaries of personhood for conceptualising stigma and discrimination associated with dementia.

One of the main boundaries of personhood is its lack of political dimension. In cognate literatures, including social gerontology, critical psychiatry and disability studies, a citizenship lens is used to promote the status of discriminated groups of people to that of an equal citizen, with the same entitlements as everyone else. These disciplines use citizenship to understand and expose discrimination against marginalized groups such as people with physical disabilities and to reframe and politicize understanding of the experiences of people with mental health conditions (Bracken & Thomas, 2001, 2005; MIND, 1999; Sayce, 2000); the scope of this work is wide ranging and goes beyond care issues to include discrimination in the workplace and communities generally. The need to promote citizenship, as well as personhood, is beginning to be recognized within the dementia care literature (Bond, Corner, & Graham 2004; Cantley & Bowes, 2004; Graham, 2004; Innes, Archibald, & Murphy, 2004). However, what it means to be a citizen, and how that differs from being a person is not only under contention generally (Bickel, 1975; Heater, 1999) but also, and more critically, remains under-theorised within dementia practice and research. A second goal of this article therefore is to review conceptualizations of citizenship in relation to people with dementia and to examine the implications of this lens for dementia practice and research.

It is not clear why a citizenship lens has not made more of an impact on dementia practice and research. The idea that people with dementia have rights has long been recognized (King’s Fund Centre, 1986) and the need to treat a person with dementia as an equal has been voiced (Kitwood, 1997a). Yet citizenship is rarely if ever explicitly used to theorize the situation of people with dementia; the preferred frame of reference in the dementia care literature is invariably personhood (see, for example, Braudy-Harris, 2002; Crisp, 1999; Jenkins & Price, 1996; Killick & Allan, 2001; Kitwood & Bredin, 1992; Malloy & Hadjistavropoulos, 2004; McFadden & Ingram 2000; Touhy, 2004). One possible reason for this apparent lack of interest is because the differences between personhood and citizenship are not discerned. Another might be that a focus on citizenship, with its emphasis on self cognizance, is not considered appropriate for people with dementia who are more extremely impaired by the condition. The sheer task involved in shifting thinking from ‘person with *dementia*, to *person* with dementia’ (Kitwood, 1997a) is another possible reason. A third goal of this article therefore is to outline the key differences between citizenship and personhood and to explain in broad terms how each is relevant to dementia practice and research.

In addition to outlining fundamental differences between personhood and citizenship, one important commonality between them is highlighted; that is the assumption that there can be a single overarching narrative or ‘truth’ for understanding human relations. This assumption is challenged in the final section, as deeper, long standing theoretical

dilemmas in the sociological literature are introduced, specifically the dilemma about agency and structure (Giddens, 2001). The article concludes by suggesting that in broadening the conceptual lens, to include citizenship and sociological ideas about agency and structure, dementia studies will be in a better position to see and treat people with dementia as not only people, but as people with power, and to conceptualize peoples' experiences of dementia, particularly experiences related to discrimination.

2. Personhood

Personhood is a contested concept. The idea dates back to the Enlightenment and the philosophies of Rene Descartes [1596–1650] and John Locke [1632–1704] on what it means to be a person. Reflecting these logical empiricist roots, traditional views of personhood focus largely upon cognitive abilities, such as consciousness, rationality, intentionality, memory, reciprocity and capacity to communicate (Harrison, 1993). Because dementia is associated with a progressive decline in these cognitive functions, the disease has historically been assumed to strip the individual of their personhood status, leading for example to a loss of self (Cohen & Eisdorfer, 1986; Herskovits, 1995).

In the late 1980s, the notion of 'personhood' was reconceptualized and introduced into the dementia literature as a critical component of the dementia experience. Challenging traditional understandings which linked it solely to cognitive functioning, personhood was revisioned as socially constructed by and within one's interactional environment. For example, Tom Kitwood perhaps one of the most recognized pioneers of this approach, defined personhood as 'a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements' (Kitwood, 1997a: 7). Kitwood, soon followed by others, began to stress the influence of interpersonal relations as an essential aspect for understanding the dementia experience, theorizing that at least some of the deterioration seen in persons with dementia was caused not by the disease process itself, but rather by how the person was treated which resulted in his or her subsequent loss of personhood (Cheston & Bender, 1999; Davis, 2004; Hughes, 2001; Kitwood & Bredin, 1992; Sabat & Harre, 1992; Woods, 2001).

At a broad level, attention to personhood in the dementia care literature explicitly displaces the biomedical model as the only approach for understanding dementia. Rather than assuming a trajectory of irrevocable decline related to the neurodegenerative changes, this perspective recognizes that performance, behaviour and quality of life are not solely determined by neuropathology but also by the personal histories, interactions with others and by how one is perceived within one's social context (O'Connor et al., 2006). Growing evidence supports the importance of broadening this vision by highlighting the inconsistencies between neuropathology and behaviour (see, for example, Franssen & Reisberg, 1997; Mitnitski, Graham, Mogliner, & Rockwood, 1999; MRC-CFAS, 2001).

At a more specific level, a focus on personhood in dementia can be credited with developing dementia practice and research in two critical ways. First, promotion of personhood has meant that the way older people with dementia are spoken about has improved dramatically over the past ten years. For example, until relatively recently, older people with dementia were often described, as if they were living 'the death that leaves the body behind' or a 'social death' (Sweeting & Gilhooly, 1997) and therefore care providers were urged to 'look after the carer' since the person (with dementia) had to all appearances died and gone (Campell, Gillett, & Jones, 1998). In addition, people with dementia were generally regarded as a 'sufferer' lacking insight into, and ability to articulate, their situation. This discourse silenced people with dementia. However, since attention was drawn to personhood and the exclusion of the perspectives of persons with dementia in understanding and influencing the dementia experience the focus has shifted to incorporating the voices and understandings of persons with dementia into both research and practice.

A result of this shift is that gradually, research has begun to emerge aimed at capturing the perspectives of persons with dementia (see, for example, Braudy-Harris, 2002; Wilkinson, 2002). This body of research now clearly documents that persons with dementia are often quite aware of their situation (Clare, 2002), and can contribute important and unique insights about their experiences and needs (Beard, 2004; Bender & Cheston, 1997; Braudy-Harris, 2002; Clare, Roth, & Pratt, 2005; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Phinney & Chelsa, 2003; Whitlatch, Feinberg, & Tucke, 2005). The net result is that since the introduction of personhood into the dementia literature, research and practice has shifted from failing to even consider whether persons with dementia have anything to say, to acknowledging that indeed they do and recognizing the importance of hearing their perspectives. Emphasis is now being placed on seeking creative and innovative research methods to overcome communication deficits associated with the condition. The use of a personhood lens has effectively and explicitly brought the person with dementia into the picture.

A second way that the shift to personhood has contributed to transformations in the culture of dementia care is by offering hope that positive change can occur. Kitwood (1997b) and others clearly accorded primacy to the interpersonal environment for helping to shape the dementia experience; the linear link between personal experience of deterioration and organic changes is challenged and one's interactions with one's worlds are recognized as having the potential to foster or erode one's sense of personal competence, uniqueness and hence personhood. This understanding promotes a shift from the disease process itself, to the interpersonal environment as the focus of change efforts. Countering the pessimism and hopelessness historically attached to working with 'the demented', the new vision offers exciting possibilities for positively influencing the dementia experience; neurological factors might not be readily modified but there is growing evidence that psychosocial interventions, environmental changes and assistive technologies can mitigate the extent of the disability and improve quality of life (see, for example, Bates, Boote, & Beverley, 2004; Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000; Kelly, 1993; Marshall, 2001; Woolham, 2006). A focus on personhood then offers hope and validates the importance of developing person-centred approaches to practice and research.

Although there has been some critical debate about person-centred care (Dewing, 2004; Nolan, Davies, Brown, Keady, & Nolan, 2004; Parker, 2001), personhood is generally accepted as a useful lens for dementia practice and research. Its impact on the field is further evidenced by significant changes over the past ten years in health and social care policy. For example, in the UK in the 1980s, persons with dementia were implicitly positioned as a burden, a drain on health and social care resources (Health Advisory Service, 1983; Ineichen, 1987), and here, like elsewhere, supportive interventions concentrated almost entirely on the needs of caregivers (Cortrell & Shulz, 1993). More recently however, UK health policy directives such as the National Service Framework for Older People have explicitly recognized persons with dementia as people entitled to quality care and services (Audit Commission, 2002; DoH, 2001). Consequently, there is a greater emphasis on user involvement in service planning and delivery, which has resulted in numerous studies which seek insights and feedback from people with dementia, as well as caregivers.

While attention to personhood in the dementia care literature has achieved much in terms of raising consciousness about the intrinsic value of individuals with dementia and offering promise that constructive changes can be achieved, it has boundaries. Several issues emerge which are particularly relevant for positioning the need to broaden the conceptual base. First, attention to personhood has promoted an individualized lens for understanding the dementia experience. Hence, conceptualizations of dementia practice and research have manifest at an individual rather than social and political level and the focus in dementia research has tended to be on the person within his or her immediate environment. For example, after ten years of care home research involving people with dementia more is known about micro level issues such as quality of care (Brooker, 2003; Netten, 1993; Tune & Bowie, 2000); communication techniques (Killick & Allan, 2001) and individual coping strategies (Bruce, 2004; Bruce, Tibbs, & Downs, 2002). However, less is known about macro level issues such as the impact of social structures related to disability, age, gender, ethnicity and social class on peoples' experiences of long term care (Cantley & Bowes, 2004). This gap raises concerns that blame may simply have been shifted for the treatment of persons with dementia from the disease process to the immediate environment, thereby failing to adequately capture how wider social problems and forces influence the lived experience of dementia. Although perhaps not inherently antithetical to the concept, with few exceptions there has been limited success in contextualising the personal experience within a broader socio-political context (Bond et al., 2004; Downs, 2000; Hulko, 2002; Innes, 2002).

Another boundary of personhood is that while it is grounded in the idea that a person with dementia is someone who counts, this lens does not necessarily promote the vision of someone with agency. Rather, personhood is conceptualized as something that is conferred upon a person with dementia, conveying a uni-directional understanding which arguably continues to position a person with dementia as passively dependent upon others for affirmation. For example, Downs (1997: 598) notes that maintaining the personhood of people with dementia essentially becomes 'the responsibility of those who are cognitively intact' rather than the individual with dementia. Even with its revisions then, a personhood lens does not explicitly recognize a person with dementia as a social actor, capable of exerting power and influence.

A third boundary is that because personhood is essentially an apolitical concept primarily concerned with psychological and health matters such as love, morality, spirituality and well being (Brock, 1993; Rudman, 1997) it does not really provide the language for discussing peoples' situation in terms of power (as opposed to psychosocial) relations. For example, a personhood lens does not have the language for exploring the possibility that 'caring' might sometimes have more to do with power and control than with values of trust and giving (Fox, 1995), nor is this lens really able to describe relationships in the context of wider social divisions. Consequently, socio-political matters such

as experiences of discrimination may be overlooked, and engagement in activities that have political (as well as personal) meaning are not seen or discussed as such.

3. Citizenship

In contrast, a citizenship lens begins to redress some of the gaps inherent with personhood. The idea of citizenship originally dates back to the Roman Empire and developments of the city—but modern notions of citizenship can be dated back to the French Revolution in the mid eighteenth century when the idea was linked to equality (Turner, 1986). More recently, citizenship has traditionally been associated with the promotion of civil, political and social rights particularly in relation to the welfare state (see Dwyer, 2004). Although the idea of citizenship originated in Western Europe, the notion that all persons should enjoy certain rights and freedoms is firmly rooted in political theory and philosophy: thus, the idea of citizenship resonates with liberal democracies worldwide (Ignatieff, 1989).

Citizenship is traditionally defined in the social science literature as a ‘status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties which the status bestows’ (Marshall, 1949/92: 18). A citizen is thus defined by the acquisition of, and participation or inclusion in, the country or community in which they live (Gould, 1988). The idea of having a ‘status bestowed’ is not new to dementia studies, and indeed reflects Kitwood’s definition of personhood. However, a fundamental difference between personhood and citizenship is that discussions about citizenship are by implication discussions about power, and in particular, the lack of power afforded to some citizens in relation to others (Twine, 1994). In this sense citizenship has deeper implications than personhood because it moves into the realm of political discourse — particularly the idea that participation or inclusion in society is inevitably shaped by power dynamics (Thomas, 2004).

From a Foucauldian perspective, the acquisition or retention of citizenship status and rights is not a straightforward process; power struggles inevitably occur (Dreyfus & Rabinow, 1982). Proctor (2001) demonstrated this in her qualitative study of women with dementia using day care services. By focusing on the socio-political context of relationships, Proctor showed how ineffective and powerless the women she spoke to felt in relation to medical staff and other health care professionals. Foucauldian ideas about power, particularly the status and disciplinary nature of medical knowledge and power (Foucault, 1967, 1980) have been a central theme in the medical sociology literature since the 1970s (Lupton, 1997). In recent years, this classic Foucauldian theme of knowledge as power (Foucault, 1980) has been used by gerontologists to show how the situation of people with dementia, specifically people with Alzheimer’s disease, has become medicalised, and in turn, disempowered people with dementia and their families (see, for example, Bond, 1992; Gilleard & Higgs, 2001; Harding & Palfry, 1997; Lyman, 1998).

Because a citizenship lens is fundamentally concerned with the (mis)use of power it has been proposed as being more apposite than personhood for understanding and combating discrimination (Shotter, 1993). Reviewing cognate fields there is evidence to support this view. For example, within social gerontology, the concept of citizenship has underpinned work on ageism (Bytheway, 1995; Turner, 1989; Vincent, 1995, 2000; Walker, 1999); productive aging (Burr, Caro, & Moorhead, 2002); social exclusion (Blackman, Brody, & Convery, 2001; Phillipson & Scarf, 2004) and models of care practice (Thompson & Thompson, 2001; Todhunter, 1999). Additionally, in critical psychiatry a citizenship lens is used to inform analysis of the experiences of people with mental health conditions within psychiatric services (Bracken & Thomas, 2001, 2005) and the general community (MIND, 1999; Rogers & Pilgrim, 2003; Sayce, 2000).

Citizenship has also assumed a pivotal position in disabilities studies where research and practice has increasingly been dominated by the belief that it is through the process of making political the personal experiences of discrimination and social inequality the situation of marginalized groups of people can be improved. Through this process, the Disability rights movement raised awareness of the denial of citizenship that people with disabilities experienced (Campbell & Oliver, 1997), and thereby enhanced the status of people with physical disabilities from ‘impaired individual’ to that of a full citizen, entitled to the same from life and their community as everyone else (Tregaskis, 2002). A citizenship lens clearly has the potential then to improve the status and treatment of disempowered groups of people.

In recent years, the emphasis in the social science literature has changed from recognition of rights and responsibilities to the practice of citizenship (see, for example, Barnes, 1997; Isin and Wood, 1999; Lister, 2003; Shotter, 1993; Turner, 1993). This change in focus redefines citizenship as not simply a status which has an attached series of actual or assumed rights, but also a practice through which individuals relate to their communities and the state

(Prior, Stewart, & Walsh, 1995). With this perspective on citizenship, political participation is more broadly defined (Lister, 2003), and citizenship moves beyond a status bestowed 'from above' to something individuals achieve for themselves, through the power dynamics of everyday talk and practice (Barnes, Auburn, & Lea, 2004). Being a citizen thus becomes something people do, rather than something they strive to be (Prior et al., 1995). For example, the attempts of people with physical disabilities to change the built environment can be seen as a 'quest for citizenship' (Paterson & Hughes, 1999: 604) as can pension protests by older people (Barnes, 1997).

The emergent theme of citizenship practices – as well as rights – in the literature, reflects the 'cultural turn' taking place within sociology generally (Nash, 2001). Political scientists, like many others within the sociological field, are rejecting, or rather deconstructing tightly structured accounts of social life in favor of more relational and culturally based explanations. Certainly, within critical psychiatry, citizenship is beginning to be seen more in terms of being able 'to define one's own identity and to celebrate this identity in different ways' (Bracken & Thomas, 2005: 81). This trend reflects a more postmodernist approach to understanding citizenship. Postmodernism defies definition as it is an approach which contests structure, categories and meaning (Bauman, 1992). Rather the approach celebrates difference — different identities, sexualities, lifestyles, cultures, worldviews, meanings, narratives; indeed any issue related to the human experience.

The issue of difference is particularly evident in discussions about the impact of globalization. Globalization refers to the growth of interconnections between states and societies (Held, 1992: 98) — a process that inevitably leads to the widespread adoption of socio-economic forces such as capitalism and commercial products like McDonalds and Nike. However, from a postmodernist perspective, globalization will also give rise to an 'increasing fragmentation and differentiation of culture' (Isin and Wood, 1999: 6). The need to recognize and celebrate difference is critical in dementia studies, as meanings of dementia are not shared across the world, indeed some cultures do not even have a word for 'dementia' (Cohen, 1998), and a man or woman with dementia, like any other citizen, will express their political agency in different ways (Bauman, 1992).

A conceptual shift to the practice of citizenship is important then, because it means the activities of people with dementia take on political as well as personal meaning. For example, members of organisations like the Dementia Advocacy Support Network International (DASNI) (see <http://www.dasninternational.org>) and the Scottish Dementia Working Group (see <http://www.alzscot.org/pages/sdwg.htm>) are doing more than maintaining their personhood; they are effectively repositioning themselves (Sabat, 2003) as active citizens rather than as 'tragic victims of a disease'. The activities of other people with dementia – out of the public eye – can also be seen as having political as well as personal meaning. For example, McColgan (2005) describes the actions of a person with dementia wanting to sit in a particular chair in a care home as an act of resistance or demonstration of resilience rather than behaviour based on cognitive decline. A lens of citizenship provides us with the impetus and language to recognise behaviour that might otherwise be seen as idiosyncratic, as the exercise of power.

The importance of making the shift to citizenship is further evidenced when one considers the potential direction of dementia care research. Currently, Alzheimer's Society, UK has people with dementia on its research review panel, and there is a small (growing) body of literature to help academic researchers involve people with dementia more creatively in the research process (see, for example, Clarke & Keady, 2002; McKillop & Wilkinson, 2004; Stalker, Gilliard, & Downs, 1999; Wilkinson, 2002). People with dementia are clearly seen and treated as important players in the research process. However, little of the research looking at user perspective has gone to the next step of either pulling together or examining what happens in research projects in a way that is political. For example, in most user perspective studies, individual needs are spoken of and contextualised using themes or general categories related to care provision; data are not generally seen in the wider political context of the need for social change (see for example, Barnett, 2000; Innes & Sherlock, 2004). Additionally, people with dementia are rarely involved in the early formulation and planning of projects, which raises questions about the relevance of current research to people with dementia. The point is not to criticize user perspective studies but to highlight how a shift to citizenship would ensure people with dementia were seen and treated as people with power, specifically people with the power to instigate and shape the research agenda.

While citizenship provides an apparently useful lens for conceptualising dementia, and fits with (developing) work within dementia studies on the socio-political context of dementia, it has limitations. One criticism levied at citizenship is that it can be used as a form of state or ideological control — this disparagement is rooted in the Marxist belief that the state will inevitably find ways of controlling 'subjects' (Dwyer, 2004). From a mental health perspective, it is possible to see how a citizenship lens might be used to manage and control people in a negative way. For example,

Gilleard and Higgs (2001: 188) note the tendency to presume that only those people with the ‘scientific civilising category of Alzheimer’s’ are entitled to be seen and treated as citizens, others ‘remain a potential or actual public burden’. Similarly, Bracken and Thomas (2005: 255) suggest that citizenship is often ‘tied to a particular view of reality, one that excludes madness’. As these authors go on to note, ‘this privileges subjectivities and ways of experiencing the world that are tied to Cartesian and rationalist assumption’. This same point is made in dementia studies. Post (2000), for instance, argues that a ‘hypercognitive culture’ alienates people with dementia, and Kontos (2005: 553) suggests an emphasis on ‘cognitive knowledge’ overlooks the embodied self. Because citizenship has the potential for excluding individuals still further, some commentators find it an unhelpful theory for understanding the socio-political world (Bickel, 1975; Delanty, 2000).

Another boundary of citizenship is that it can lack an individual dimension. A traditional view of citizenship is grounded in the premise that every one wants, and should have the same rights and responsibilities. As one feminist notes, these ‘rights are represented as essentially abstract and universal and therefore not very amenable to a politics of difference’ (Lister, 2003: 87). The problem with this is that internal differences within a social group are denied and ‘the fact that every individual has multiple identities and social roles’ overlooked (Faulks, 2000: 91). Certainly, a citizenship lens has been criticised for rendering older people into an ‘undifferentiated group who need to be made equal’ (Higgs, 1997: 122). Clearly dementia practice and research does not need a lens that treats people with dementia as a homogenous group.

4. Towards a more inclusive lens for dementia practice and research

The lenses of personhood and citizenship then, each offer unique contributions to understanding and responding to dementia. Table 1 outlines the contrasting elements of personhood and citizenship and illustrates how each lens promotes a different aspect of the experience to be seen.

Since each concept has different historical roots, it is not surprising the two have distinct emphasis from one another. For example, a personhood lens has typically resulted in questions regarding whether or not people with dementia can have personhood (Davis, 2004; Hughes, 2001) whereas a discussion of citizenship assumes personhood but queries the set of rights and responsibilities affiliated with that status. Each also brings a different perspective on experience. Personhood emphasises the uniqueness of human experience whereas citizenship is traditionally associated with the idea of a collective experience, and championing what people share – or should share – most notably an ‘equality of status’ and opportunities (Marshall, 1949/92, cited in Dwyer, 2004: 40). Unsurprisingly given their different foci and emphases, a different set of questions is asked through each lens.

To date, almost all questions related to dementia practice have been addressed through a personhood lens. Even questions related to socio-political issues have tended to be theorised using personhood. Clearly though, there is not only the potential, but also a growing need, to broaden the conceptual base for dementia practice and research to include citizenship. While once contested, at least at a pragmatic level within the health and social practice the personhood of people with dementia is now considered undeniable; what remains at stake are peoples’ rights and practices as citizens.

Maintaining personhood was only ever meant to be part of the care agenda in dementia studies (Kitwood & Bredin, 1992); not the entire agenda. By embracing citizenship, the socio-political research agenda the field has been calling for, and is beginning to develop, has a more apposite lens through which to expand. For example, empirical research into peoples’ experiences of stigma and discrimination, which has been absent from the field (Bond, 1999), but which is beginning to develop (Daker-White, Beattie, Means, & Gilleard, 2002; Gilliard, Means, Beattie, & Daker-White,

Table 1
Contrasting elements of personhood and modern citizenship

	Personhood	Modern citizenship
Historical roots	Psychology, moral philosophy	Political philosophy
Level of entitlement	Needs-based	Rights and responsibilities
Position of self	Singular	Collective
Conferment of status	Moral, ethical	Constitutional
Type of experience	Unique (individual)	Common (shared)

2005; Jolley & Benbow, 2000; Katsuno, 2005), may broaden to include peoples' experiences of discrimination at work and within local communities and society at large. The main benefit of moving beyond personhood to include citizenship then, is that it immediately extends and supports the research agenda beyond care issues to wider socio-political matters. A citizenship agenda could therefore improve not only dementia care, but also the general treatment of people with dementia within society.

Incorporating a notion of citizenship into dementia practice and research is indeed challenging. Certainly, while the understanding that persons with dementia *should* be accorded full citizenship may be accepted, it must also be acknowledged that deteriorating cognitive abilities may limit a person's abilities to exercise associated rights and practices (Karlawish et al., 2004). Dementia is, after all, a formidable 'mental obstacle' (Walker, 1999). However, with the advent of new health technologies and approaches, such as anti dementia drugs, which may help slow the progression of the disease and/or help persons with dementia feel better about themselves for longer periods of time (Ibbotson & Goa, 2002; Rockwood, Wallack, & Tallis, 2003; Romero & Wenz, 2001), expectation that persons with dementia will – and should – be able to contribute politically for longer periods of time is anticipated. The challenge is to develop an understanding of citizenship that is 'unconditional and inclusive' rather than dismiss the concept out of hand (Bracken & Thomas, 2005: 256).

5. Bringing sociological theory into the lens

The debate about personhood and citizenship represents a type of micro–macro problem that is central to social theory. That problem, at its simplest, is how individuals connect to wider society. Giddens (1979:49) describes the dilemma in terms of trying to establish the extent to which 'human action and structural explanations' are interconnected — or, as he has said more recently, how far any individual is in charge of their own actions, as opposed to them being the result of social forces (Giddens, 2001). This particular theoretical dilemma has beset social scientists for over a century, and yet further theorising is still necessary, particularly in relation to the capacity of individuals to deal with structuring forces (Emirbayer & Mische, 1998), like age, gender and disability.

The advantage of thinking about agency and structure in relation to people with dementia is that it repositions the superiority of personhood and citizenship, and fosters further conceptualising that is potentially useful for dementia practice and research. For example, while useful lenses, both personhood and citizenship have to date drawn on more essentialist understandings of identity and 'being in the world' that result in examining each as if it can either be present or not present, and if present, treated as unchanging and fixed. The focus on personhood has been particularly essentialist; when applied to persons with dementia, the argument has simply moved between the question of whether or not persons with dementia have personhood to how to 'maintain personhood'. This shift allows no room for growth and change on the part of the person with dementia, and separates 'the dementia' as though it does not matter for shaping the experience. As Clarke and Marshall (2001) found in their study of how older people adapt to a stroke, the interaction between wider social structures and experiences of ill health is far more complex than this. Moving forward with the discussion suggests the need for a further shift beyond Kitwood's notion of *person* with dementia (Kitwood, 1997a,b) to *person with* dementia.

Citizenship can also be essential as it sees people as having a set of rights and responsibilities that are inherent, failing to recognize or take account of how this will change with the dementia process. One could argue that the state of knowledge has simply not moved this far — that is, we do not know how dementia affects peoples' sense of citizenship. However, at a broader level it can also be argued that discussions about citizenship have generally failed to address the complexities associated with being a citizen — for instance, how can it be exercised, and where is it limited on an individual basis.

Clearly the challenge for dementia practice and research is to not privilege any particular view of what it means or takes to be a person or citizen — on the contrary, it needs to recognize micro *and* macro influences and see subjectivity as being created through 'acts of power' (Fox, 1993: 11). So rather than having to wait passively for a status — moral, constitutional or otherwise — to be 'bestowed', an individual is seen as having the power to 'turn him or herself into a subject' (Dreyfus & Rabinow, 1982: 208). Persons with dementia are thus seen simultaneously as both actors in constructing their own reality, and constructed by prevailing discourses. Researching peoples' experiences of dementia from this theoretical perspective involves asking questions about the societal context in which people live — that means, asking questions about age, gender, ethnicity and class, as well as the actual embodied experience of impairment (Thomas, 1999). With few exceptions, dementia care research tends to focus on either individual

experiences of dementia or the wider social-political context. Few studies take full account of the wider context in which experiences are taking form (see, for example, Gilliard et al., 2005; McCabe, 2006; Proctor, 2001). With a broader sociological theoretical base, future studies of the dementia experience may go into more depth, and be in better position to analyse the influence of micro and macro processes on experiences of dementia.

6. Conclusion

In this article, it is argued that the lenses of personhood and citizenship need to combine and recognise sociological ideas about agency and structure to create a broader lens for dementia practice and research. Personhood can not fully explain the essence of power relations and citizenship can not fully recognise the essence of individuality. Moreover, neither lens fully grasps the complexities of human experience, particularly the relationship between self and society. One of the key discussion points is that personhood and citizenship represents a type of micro/macro problem which has beset social scientists for many years. By broadening the conceptual lens to include citizenship and sociological ideas about agency and structure, the anti-discriminatory practice and socio-political research agenda the field has been calling can move forward.

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