

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

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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.

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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 and are more likely to be

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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

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