Identity, selfhood and dementia: messages for social work

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Denise Tanner

Dementia has been identified as a policy priority area for the European Union (EU). Given projected figures on the global increase in dementia over the next few decades, working with people with dementia is likely to become an even more prominent area of activity for social workers in older people's services. Recent research has begun to engage with the subjective experiences of people with dementia and there is considerable focus within nursing literature on their active efforts to maintain identity and selfhood. However, these issues have received little attention within the domain of social work. This paper reviews recent research on the subjective experiences of people with dementia and discusses the implications for social work in relation to: early intervention; communication and assessment, and support arrangements. Based on experience in England, it is argued that the current policy and practice context constrains social work's ability to respond to these issues and that a supportive organisational context, as well as high levels of skill, time and commitment, are required if concepts of personhood and citizenship are to have meaning in practice.

Keywords: Dementia; Older People; Identity; Personhood; Practice

Introduction

Around 35.6 million people worldwide are estimated to have some form of dementia, 9.9 million (28%) of whom are located in Europe. The worldwide figure is projected to increase to 65.6 million by 2030 and to 115.4 million by 2050 (Alzheimer's Disease International, 2010). These figures reflect a global ageing population. Prevalence increases with age; while around 6% of individuals aged 65 and above are estimated to have dementia, this increases to around 30% for those in their eighties (Luengo-Fernandez *et al.*, 2010). Given the potential health and social care cost implications, it is unsurprising that dementia is a growing policy priority across the European Union

(EU) (Bamford, 2010). One of the national actions proposed by the European Parliament (2011) is to improve the well-being and quality of life of people with dementia.

In the UK, approximately two thirds of people with dementia live in the community (Alzheimer's Society UK, 2010), but there is a lack of detailed and reliable information about the number receiving social services support (Care Quality Commission, 2010). While 68% of people receiving any type of social service in England in 2008–2009 were aged 65 and above (NHS Information Centre, 2010), it is not possible to ascertain how many of these were people with dementia. Medical practitioners' uncertainty about and/or reluctance to disclose dementia diagnoses (Fortinsky, 2008), along with the coexistence of dementia with other physical and mental health difficulties, mean that dementia may be obscured in terms of its prevalence and significance for service use.

In terms of the eligibility criteria operated by councils with social service responsibilities for adults in England (Department of Health, 2010a), cognitive, emotional and physical changes associated with dementia, such as memory loss, impaired judgement and reduced ability to undertake activities of daily living (Phinney, 2008), may present risks to individuals' independence, increasing the likelihood they will require assessment of their need for services and assistance to arrange support services. Social workers, especially those in multi-disciplinary teams, are likely to be primarily exposed to biomedically-oriented understandings that view dementia as a disease process involving progressive decline and loss of selfhood. Although the National Dementia Strategy in England (Department of Health, 2009)[1] is seen as a move towards a social model, research with health and social care professionals indicates that the legacy of the medical model remains intact (National Audit Office, 2009). The danger is that this model 'restricts our understanding of the "emotional world" of people with dementia and potentially misinterprets or renders meaningless their actions' (Beard, 2004, p. 418).

This paper discusses recent research that engages with the subjective experiences of people with dementia, highlighting issues of personhood and identity, before proceeding to consider the implications for social work practice.

Personhood

Tom Kitwood's work has been highly influential in challenging the medical paradigm of dementia and advancing an understanding based on the interaction of personal, social and neurological factors. Central to his work is the concept of personhood, defined as, '...a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood, 1997, p. 8). Whereas 'the standard paradigm' focused on inevitable loss and decline, personhood affords the potential to transform the experience of living with dementia through changing the social responses to it. Kitwood (1993a) argues that a diagnosis of dementia is a signal for a specific type of

social response, and that as the dementia advances social processes become more important in supporting individuals to maintain a sense of self. How others respond to the person with dementia is therefore the crux of the dementia experience (Sabat & Harré, 1992; Surr, 2006). From this starting point, Kitwood developed detailed exposition of 'the malignant social psychology' of dementia (Kitwood, 1997) and the action and approach needed to create 'a new culture of dementia care'.

However, some revision and expansion of personhood may be needed. Dewing (2002) suggests that the concept of personhood as a status bestowed on an individual serves to increase exclusion, since it is dependent on the behaviour of others. She proposes that personhood is instead seen as, '...a moral entitlement rooted in an embodied self and manifested through social relations based on a concern for others' (p. 160). Bartlett & O'Connor (2007) acknowledge that personhood has been beneficial to people with dementia, promoting recognition that they have a voice as well as offering therapeutic possibilities through changing the interpersonal environment. However, they also raise limitations: it concerns the person in their immediate social environment, but not in relation to the wider socio-political context; it recognises that the person with dementia matters, but not that the person has the capacity to exercise agency; and it limits itself to individual health and well-being, without examining how power shapes relationships. They suggest that personhood should be combined with citizenship, so that the limitations of each can be offset by the other: personhood recognising individuality and citizenship foregrounding power relations (p. 115). Applying this to research, while the concept of personhood indicates the imperative to include the voices of people with dementia, citizenship recognises their capacity for agency and right to have influence and control in relation to research processes (Bartlett & O'Connor, 2007).

Learning from research: hearing seldom heard voices

There has been limited research on the experiences of people with dementia (Dewing 2002; Moore & Hollett 2003), with studies tending to focus on either the experiences of carers, whether as direct 'service users' in their own right or as 'proxy' informants speaking for people with dementia, or people in the early stages of dementia (Downs 1997). There are understandable reasons for this, not least thorny issues concerning capacity and consent and the difficulty of obtaining approval from Research Ethics Committees (Frankham 2009; McKeown *et al.*, 2010). However, as Dewing (2002) points out, a concern with 'doing right' in research can, if narrowly interpreted, amount to 'exclusionary ethics', preventing the participation of people deemed to be vulnerable.

There is evidence that older people's mental well-being is enhanced by activity and social engagement (Medical Research Council, 2010) and that they derive various personal benefits from involvement in research more specifically (Ross *et al.*, 2005). Benefits to people with dementia from involvement in research include the enjoyment of sharing their stories, enhanced self-esteem, social activity and sense

of making a contribution and being valued (Mills, 1997; Proctor, 2001; Aggarwal *et al.*, 2003; Cantley *et al.,* 2005; Edvardsson & Nordvall, 2007). Excluding people with dementia from participation in research not only deprives them of the opportunity to offer views and experiences that could contribute to service improvement; it also denies them of some of the more therapeutic benefits that may accrue from involvement (Dewing, 2002). Involving people with dementia in research is thus a route to addressing their social exclusion (Cantley *et al.,* 2005; Ward *et al.*, 2008). It is the responsibility of researchers to find ways of communicating with people with dementia (Goldsmith, 1996) as exemplified in the reconstruction of people with dementia as 'seldom heard', rather than 'hard to reach' (Robson *et al.*, 2008), and some researchers are responding to this challenge (Hernandez *et al.*, 2010). The Identity Section discusses findings from research undertaken with older people with dementia that highlight the significance of issues of selfhood and identity.

Identity

Identity is intrinsically social in nature in that individuals develop their sense of self in the context of interaction with others. There is no distinct and immutable 'private' self since this is partially constituted from reactions to the 'public' person (Jenkins, 1996). Sociologists from the fields of symbolic interactionism and ethnomethodology attest to the powerful role of others in creating, confirming and/or perpetuating particular identities in those perceived as 'deviant' or 'outsiders' (Becker, 1963; Scheff, 1966; Goffman, 1968). Negative social responses from others constitute direct threats for sense of self: 'Public image may become self-image. Our own sense of humanity is a hostage to the categorising judgements of others' (Jenkins, 1996, p. 57).

The responses and behaviour of others are seen as key influences in determining selfhood for people with dementia (Clare, 2003). Kitwood's definition of personhood, presented previously, 'implies recognition, respect and trust' (Kitwood, 1997, p. 8); in other words, it signifies communication of a valued social identity. However, it remains the case that to be a 'demented person' is highly stigmatising (National Audit Office, 2010). People with dementia are commonly depicted as having suffered a 'loss of self', as existing in a state of a 'living death' and as 'zombies' (Behuniak, 2011). The diagnosis itself may be experienced as an 'assault on self esteem', since, ' . . . once a person has been identified as having dementia, it is almost as if they have lost the right to define their own identity. Dementia trumps everything else' (Killick & Allan, 2001, p. 26). Care practices may unwittingly reinforce a negative identity (Parker, 2001). Askham *et al.*'s (2007) research with older people with dementia in care homes observed the presence of negative features of institutional care noted by Goffman, such as mortification through treating residents like children, depriving them of roles and acting as though they were not there. These practices were by-products of attempts to ensure the efficient running of the home, but residents' identities were 'soiled' in the process.

However, as Bartlett & O'Connor (2007) argue, personhood does not give sufficient weight to individual agency. Identity is not just imposed by the social reaction; individuals are actively involved in creating and renegotiating their identity. Giddens (1999) refers to 'the reflexive project of the self' as self-identity is continually renegotiated and 'reflexively understood by the person in terms of her or his biography' (Giddens, 1999, pp. 52–53, emphasis as original). Giddens argues that individual identity resides in the capacity to keep 'a particular narrative going'; individuals are involved in maintaining an 'ongoing 'story' about the self that integrates individual biography with external events (p. 54). Biggs (1999), writing specifically on identity in later life, also sees identity as 'a concept at the crossroads of the personal and the social' (p. 3). He argues that in later life identity becomes more fluid and strategies for managing identity become more sophisticated (Biggs, 1999). He invokes the concept of 'masquerade' to describe the adaptive process through which individuals respond to perceived threats within different social environments. If the social space is evaluated as supportive, aspects of self may be revealed that would be concealed or underplayed in environments perceived as more hostile. A key issue is therefore individuals' assessment of the extent to which the social space is supportive of their 'inner self'.

These perspectives on identity indicate important areas to consider in relation to working with people with dementia: the nature of the social space and social reaction of others, but also the individual's reflexive interpretation of self, evaluation of the social environment and identity management strategies. The Preserving selfhood Section considers research that elucidates these areas.

Preserving selfhood

The relevance of identity and identity management to understanding and responding to people with dementia depends on the extent to which a sense of self is retained. While Davis (2004) argues that from carers' perspectives, dementia brings 'a very real dismantling of the self' (p. 378) that needs to be acknowledged, Downs (1997) and Beard (2004) refute the view that dementia involves a progressive loss of self. From her research on the subjective experiences of older people recently diagnosed with Alzheimer's in San Francisco, Beard concludes,

> . . . identity construction is a deliberate, if shifting, accomplishment for people with dementia rather than simply an illness where self-identity increasingly vanishes (Beard, 2004, p. 417).

A key theme she identified, 'Preservation', was concerned with the strategies used to manage social identity and communication. Older people with Alzheimer's and their carers were engaged in efforts to retain a sense of the enduring self:

> . . . people attempt to maintain an image, both publicly and personally, of a self that is ultimately in danger of being shattered. These people try to resist being assigned

the 'master status' of a 'demented' person by preserving the social personae as was intact prior to memory loss (Beard, 2004, p. 425).

Based on in-depth interviews with nine people diagnosed with Alzheimer's in Canada, MacRae (2010) identifies a range of different strategies used by participants to manage their identity. These include normalising experiences such as memory loss, adjusting their aspirations in the light of changing abilities and making positive social comparisons. Similarly, Phinney (2008) reports on the strategies people used to live positively with dementia, such as minimising the impact of dementia, finding ways to help others, utilising humour and maintaining a sense of hope.

Maintaining a sense of hope was one of the cognitive strategies used by older people with dementia due to relocate to a care home in Canada; others included 'reframing' their experiences in positive terms and normalising their deterioration (Aminzadeh *et al.* 2009, p. 493). Wolverson *et al.* (2010) explored the importance of hope in sustaining a sense of well-being in people with early stage dementia. They identify two main themes: 'Live in hope or die in despair', highlighting the tension between 'hope-fostering beliefs and hope-hindering experiences'. This research demonstrates that the strategies used by older people with dementia are grounded in an awareness of their situation, rather than an inability to engage with it. Wolverson *et al.* refer to participants' 'contextual realism' in that they talked about difficult situations and experiences, such as loss of role and respect, being ignored and awareness that they were not going to get better. However, based on their understanding of the realities of their situations, they were able to adjust their expectations, employ coping strategies and find new ways of experiencing hope. Wolverson *et al.* suggest that through an ongoing process of adjusting their hopes as their circumstances change, participants are able to protect themselves against despair and retain a (revised) sense of hope (p. 456). Like Beard and MacRae, they note the parallel themes with theory and research on managing loss and change in later life more generally. Indeed, as Beard (2004) points out, 'Respondents were involved in the same process of identity preservation that we all are' (p. 426).

However, it seems that identity management is complex, dynamic and nuanced, influenced by individual differences as well as contextual factors. Pearce *et al.*'s (2002) research with men recently diagnosed with dementia found that they were involved in negotiating a tension between a desire to maintain a sense of their former self and the need to reappraise their lives and construct an altered self in line with the changes associated with dementia. This is also highlighted in Clare's (2003) study, which explored awareness of change in 12 people in the early stages of Alzheimer's. Similar to Pearce *et al.*, Clare notes '. . . a tension between attempts to protect the self from threat and attempts to engage with the potential threat and integrate the resulting experience into the self' (p. 1021). She suggests that responses are located along a continuum between self-maintaining strategies, which endeavour to normalise and minimise changes, and self-adjusting strategies, based on efforts to address the difficulties and adjust the sense of self. She argues that different responses are adaptive for different individuals. Clare also identifies five interrelated processes

when dealing with awareness of having dementia. The five processes—registering awareness, reacting to it, explaining to others, experiencing dementia and adjusting to it—are dealt with differently according to whether a self-maintaining or self-adjusting theme is adopted. For example, in the process of experiencing dementia, individuals might favour a self-maintaining theme of 'putting on a protective coating' or a self-adjusting theme of 'spending time in the depths' (Clare, 2003, p. 1022). In interviews with the 12 original participants one year later, Clare (2005) found continued evidence of the continuum between self-maintaining and self-adjusting themes, but these were not necessarily consistent with the styles demonstrated in the earlier interviews. Overall, she found a prevalence of self-maintaining strategies. She sees self-adjusting styles as reflecting a higher level of awareness of the changes and impairments associated with having dementia and she suggests that over time, as the dementia progresses, coping styles may change.

Implications for social work

If the 'self' is a product of social interaction, and the need to preserve a sense of self remains intact, then enhancing dementia care necessitates addressing the attitudes and behaviour of those in the person's social environment. However, this is about more than 'treating people with dementia better' in any straightforward, unidirectional manner. If people with dementia are actively involved in efforts to manage their identities, including the threat posed by awareness of having dementia, it also requires understanding and support of their identity management strategies. The Early intervention Section discusses the implications for social work in relation to early intervention; communication and assessment; and support arrangements.

Early intervention

Early intervention with people with dementia is hampered by delay, vagueness and euphemisms encountered in diagnostic practice (Bamford *et al.*, 2004). The need to be informed of a dementia diagnosis is recognised by Alzheimer's Europe (2009) and in revised Dementia Strategy in UK, which prioritises 'good quality early diagnosis and intervention' as one of four priority areas (Department of Health, 2010b, p. 10). In addition to moral arguments about people's right to information about their health, early diagnosis and intervention brings practical and therapeutic benefits (Gilliard *et al.*, 2005; Milne, 2010a), as well as gains in cost-effectiveness (Banerjee & Wittenberg, 2009).

Receiving a dementia diagnosis is a significant social and psychological event in the lives of those affected (Vernooij-Dassen *et al.*, 2006; Milne, 2010a). Autobiographical accounts by people with dementia demonstrate that they recognise the threat to selfhood posed by the diagnosis (Page & Keady, 2010). Beard's (2004) study of older people recently diagnosed with Alzheimer's found that they were aware of the reactions of others and took this into account when evaluating the advantages and disadvantages of 'telling'. Langdon *et al.* (2007) found that people with early stage

dementia were acutely sensitive to people's reactions to them and cautious about sharing their diagnosis beyond the circle of immediate family and friends. They were aware of their loss of role and social status and this had negative consequences for their self-esteem.

Social workers can help individuals to explore what having a dementia means in the context of their lives and identities (Manthorpe & Iliffe, 2005). Core professional values and skills, including openness, genuineness, respect and empathy, equip social workers well for this role. Individuals with dementia are sensitive to concealment and inauthentic responses from others and want to be treated with honesty and openness (Langdon *et al.*, 2007). The changes associated with dementia can trigger difficult emotions, such as fear, anxiety, sadness, and anger, yet people with dementia are often not afforded the opportunity to explore or make sense of their feelings (Aggarwal *et al.,* 2003; Phinney, 2008; Rewston & Moniz-Cook, 2008). An emotionally intelligent response from the social worker will recognise and respond empathetically to these emotions (Howe, 2008), rather than viewing them as part of a disease process.

Communication and assessment

Social policy and practice, at least in the UK, has not taken adequate account in its development of the growing number of older people with dementia (Dementia Action Alliance, 2010). The current vision for adult social care in England is encapsulated in the concept of 'personalisation', incorporating a number of key objectives and principles. Advice, information and advocacy should be available to improve people's access to services, including universal services, and enable them to make informed choices. Self-directed support, whereby individuals are allocated a personal budget, based on their assessed eligible needs, and then accorded control in terms of how to spend the budget to achieve their desired outcomes, should become the norm. Furthermore, new ways of designing and delivering services in collaboration with local communities should be developed (Carr, 2010). However, the core notions of responsibility, active citizenship and prevention of dependency (Department of Health, 2010c, p. 5) on which the policy is founded are not easy bed-fellows of dementia. For example, there are various specific barriers that limit access to personal budgets by people with dementia (Kinnaird & Fearnley, 2010) and potential tensions between personalisation and safeguarding that are particularly pertinent to them (Lymbery & Postle, 2010). While personalisation encourages the use of mechanisms of self-assessment, these are unlikely to be appropriate for people with dementia (Lymbery & Postle, 2010). However, while capacity assessment forms part of the process of self-directed support and risk management (Duffy & Gillespie, 2009), those deemed unable to make a specific decision about their care may still be able to contribute to assessment by communicating their needs, preferences and view of the world (Westius *et al.*, 2010).

Helping people with dementia to explore their biographies can give them a sense of meaning and continuity as well as providing useful information for assessment (Westius *et al.*, 2010). While it may be tempting for busy practitioners to dismiss the reminiscences of older people with dementia as irrelevant, focusing on the past may represent a coping strategy, rather than a reflection of short-term memory loss. In interviews with people with dementia in Sweden about their experiences of being in a psycho-geriatric unit, Edvardsson & Nordvall (2007) found that participants felt more comfortable talking about the past:

> In these moments participants could once more become persons behind the debilitating disease narrating their stories of themselves as individuals with histories, abilities, intriguing experiences and respected identities...Arguably, such stories that provide vivid accounts of a personal life and identity can lay the foundation for an alternative interpretation of the patient as a person, both for the narrator and for listeners (Edvardsson & Nordvall, 2007, p. 496).

Narratives about the past also enable people to preserve a sense of continuity with their 'former selves' that still form an integral part of their identity (MacRae, 2010).

Approaching assessment with an open vision may encourage such 'selves' to become visible. Research on subjective experiences of dementia contributes useful pointers to effective communication and relationship-building. One man with dementia who had participated extensively in research interviews as both 'subject' and researcher gave as one of his 'top tips', 'Be yourself at all times and do not contrive to be anything other' (McKillop & Wilkinson, 2004, p. 120). A decline in cognitive skills may be compensated by heightened emotional sensitivity (Brooker, 2008). This indicates not only that discomfort or lack of authenticity by the practitioner may be detected, but also that the practitioner needs to be keenly attuned to the emotional content of the person's communication. However, the policy and practice context of much statutory social work with adults in England is that of 'heavy workloads, characterised by high-volume, low-intensity practice' (Lymbery & Postle, 2010, p. 2510), diminishing the opportunity to attend to nuances of communication and relationships. In terms of making sense of communications, Proctor (2001) found that the stories told by women with dementia were fragmented, requiring careful interpretation. In the same way that researchers have noted the need for detailed study of interview transcripts to find patterns and ascertain meanings (Moore & Hollett, 2003), so too assessment interviews may benefit from audiotaping and transcribing to help derive meaning (Brooker, 2008). Attending to the emotional content may yield insights even when the spoken words do not seem relevant (Brooker, 2008). Such communication involves, '...exploring a different intelligence and creativity that relies more on the emotional, sensitive and empathetic interactions of people rather than on their verbal expressiveness' (Hubbard *et al.*, 2003, p. 360). This is time-consuming, challenging and skilled work.

The nature of support

There is growing evidence of the benefits of rehabilitation for people with dementia (Mountain, 2005). For example, forms of cognitive rehabilitation, while not a remedy for problems such as memory loss and cognitive impairment, can nevertheless help people with dementia to maintain well-being and quality of life (Clare, 2005). Providing opportunities for people with dementia to engage in creative self-expression, through means such as music, drama, visual art and story-telling, can help to improve communication, social relationships, emotional well-being and self-esteem (Lee & Adams, 2011). Understanding individuals' self-identity can provide the basis for personalised interventions that improve emotional well-being and reduce agitated behaviours (Cohen-Mansfield *et al.*, 2006). Moreover, taking account of individual identity management can alert social workers to the particular coping style and strategies favoured by the individual. For example, Clare's (2003, 2005) findings suggest that for people who adopt a self-maintaining stance, it may be more appropriate to focus on maintaining continuity as far as possible with existing activities and relationships; for those whose narratives feature more self-themes, it may be more helpful to acknowledge disjunctions with the life as previously lived, focusing more on adaptations and change. As Clare found, however, people's stances may change over time, requiring corresponding adjustments in the nature of the response.

As dementia is a progressive condition, effective support is likely to involve helping people to manage change. Aminzadeh *et al.* (2009) findings on the cognitive strategies employed by older people with dementia relocating to a care home, referred to earlier, highlight the potential to support people through processes of change. The researchers refer to the older people's 'preparatory strategic approach to a life transition' (p. 493), suggesting that subjective factors and internal resources play a key part in determining successful transitions. Social workers can help people to manage transitions by discovering, engaging with and bolstering protective cognitive strategies.

The potential value of communication and relationships between people with dementia in preserving selfhood has been neglected in the literature (Kitwood, 1993b; Killick & Allan, 2001). Objective 5 of The National Dementia Strategy in England (Department of Health, 2009) concerns the development of structured peer support and learning networks for older people and their carers. However, the document notes that the potential of peer support depends on early diagnosis which, as noted earlier, is often problematic. There is also a danger that networks are more geared to mutual support of carers than facilitating peer communication between people with dementia. Staff judgements about individuals' capacity to communicate may be one of the barriers that need to be overcome (Ward *et al.*, 2008). Ward *et al.* (2008) observed that older people with dementia in a care home 'craved the opportunity to be socially engaged' (p. 637) and all had their own diverse and unique means of self-expression, with the potential to develop meaningful communications with others:

> Far from being a condition that erodes a person's capacity to communicate, we have found that dementia generates an array of creative responses from those affected by it, in an effort to connect meaningfully with others (Ward *et al.*, 2008, p. 648).

The researchers highlight the need for each individual's methods of self-expression to be understood and for each person to have the opportunity 'to engage meaningfully with others and maintain a social presence' (Ward *et al.*, 2008, p. 646). Given Ward *et al.*'s findings that forms of self-expression are highly individualised, simply bringing people together in the same place is unlikely to suffice; facilitating peer support is likely to require a more proactive approach by practitioners, involving the deployment of advanced communication skills and emotional intelligence.

Conclusion

The rights of older people to a life of dignity and independence and to participate in social and cultural life is enshrined in EU Charter of Fundamental Rights (Article 25) (Bamford, 2010). Embracing personhood and citizenship as pivotal concepts around which to plan and deliver social work and social care services for people with dementia can help to advance these rights. However, it also poses key challenges within the current policy and practice context. Parker (2001) made this argument 10 years ago in relation to the context of care management in the UK; similar and additional questions and issues now need to be addressed in the context of personalisation. Some tensions and challenges reflect those confronting social work with adults more generally, namely the co-existence of rationing and targeting with early intervention and concerns about how principles of choice can be balanced with protection and risk management (Lymbery & Postle, 2010). These issues have additional salience in work with older people with dementia. Early intervention can play a crucial role in supporting people practically, cognitively and emotionally, but this may be frustrated by limitations in diagnostic practice, as well as by eligibility criteria that confine service provision to those with 'critical' needs.

The key role of the social reaction in shaping individuals' reflexive interpretation of what it means to have dementia indicates the need to locate work with people with dementia in a wider social context that includes both those in the caring network and the wider community. As MacRae (2010) argues, 'No matter how positively persons with Alzheimer's Disease (AD) define the situation themselves, the success of their efforts to manage identity will depend on the support and cooperation of others' (p. 301). Concealment, fear, embarrassment and stigma are likely to contribute to a perceived hostile social space and need for masquerade (Biggs, 1999). Given the negative consequences for the individual's sense of self, it is crucial that public attitudes, staff practices and self-stigmatisation are addressed. The wider dissemination of research findings on subjective experiences of dementia and the positive strategies by which people live well with dementia can play a valuable role here (Milne, 2010b). Further research is needed on how people with dementia

communicate and relate to one another since peer support has the potential to address stigma at both individual and social levels.

With more people being diagnosed with dementia as a result of demographic changes and the move to earlier diagnosis, there are pressing concerns about the staff resources required to provide an effective service (National Audit Office, 2009). Statistics on characteristics of the social care dementia workforce in England indicate that there are higher proportions of agency workers, part-time workers and workers with no relevant qualifications than other parts of the social care workforce (Hussein, 2010). The research examined in this paper highlights the complexity of communication, relationship-building and assessment in work with people with dementia, and this has clear and pressing implications for the knowledge, skills and values required for sensitive and effective practice.

An approach based on citizenship and personhood involves recognising the capacity of people with dementia to respond and adapt to the experience of having dementia and to the ongoing changes entailed. Sensitivity is required to what having a dementia means for the individual's sense of self and how this is influenced by social reactions. The research findings considered in this paper offer insights about identity management strategies deployed by people with dementia and these in turn contain important messages for social workers, particularly concerning communication and relationships. For example, facilitating opportunities for people to relay narratives about the past and discuss hopes for the future yield valuable information for assessments, but also have a therapeutic role in supporting selfhood; ascertaining individual coping styles and strategies assists support planning. This constitutes a far wider, more complex and continuing remit for social workers than identifying 'services', not least because people's needs and strategies may change as the dementia progresses (Clare, 2005). At a time of major change and serious retrenchment in health and social services across Europe, the findings reviewed here are a salutary reminder of the time, energy, creativity, sensitivity, and advanced communication and interpersonal skills required if concepts of personhood and citizenship are to have meaning in social work practice with people with dementia.

Note

[1]   EU Member States with dementia action plans or strategies are UK, France, Norway, Netherlands and Italy (Bamford, 2010).

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