

Progress Report

The Emergence of the Person in Dementia Research

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Introduction

The purpose of this review is to identify and explore the emerging attention being paid to the individual in dementia research. Following a brief introduction, the review will examine literature which recognises three aspects of the person with dementia: the individual's sense of self; the person's rights; and the value to be gained from a concern with the perspectives of people with dementia. To date the medical model has dominated dementia research. This model tends to reduce the person with dementia to his/her neurobiology or neuropsychology (Cotrell and Schulz 1993). The experience and manifestation of dementia has been attributed solely to the disease process, with a consequent neglect of the psychosocial context surrounding the individual (Lyman 1989). Research on the psychosocial aspects of dementia has concentrated on family carers. Keady (1996) provides a useful categorisation of this research into the following topics: gender and coping style; marital relationships and the impact of dementia; access to information and services; participation in and effectiveness of support groups; adjustment and circumstances surrounding admission into care; and perception of own health needs. No literature focuses on people with dementia.

The individual's sense of self

Until recently it was assumed that people with dementia experienced a steady erosion of personality and identity to the point at which no person remained (Kitwood and Benson 1995). In their book *The Loss*

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of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders, Cohen and Eisdorfer (1986) present both the traditional and the emerging senses of the person in dementia research and care. The traditional view of people with dementia is that the person has disappeared (Kitwood 1993*a*, 1993*b*). Dementia is described as leading to 'the inexorable dissolution of self' and 'the complete loss of self'. The emerging sense of the person with dementia is also noted by the authors: while acknowledging that dementia is a 'cruel disorder', they make clear that the 'essential humanity of the person turned patient remains', for 'people do not consist of memory alone' but 'have feelings, imagination, desires, drives, will and moral being' (Cohen and Eisdorfer 1986: 22).

Gilliard suggests that the representation of the person as 'having disappeared' may result from family members' inability to keep up with the changing personality of the person with dementia. Given the demands on caring which the dependencies associated with dementia impose, families have neither the emotional energy nor the time to re-orient themselves to the personality changes which are occurring in their relative (Gilliard 1997, personal communication). Clarke (1996) examined how family and formal carers conceptualise caring for someone with dementia. Her research suggests that while families strive to preserve the relationship and keep things 'normal', providers tend to see the person only in terms of their illness and the problems it causes.

In recent years the notion of the complete loss of self has been challenged (Kitwood 1990, 1993*a*, 1993*b*; Kitwood and Bredin 1992; Kitwood and Benson 1995; Sabat and Harré 1992). This philosophy of dementia care challenges traditional approaches (Keady 1997, personal communication). People with dementia are presented as people with unique biographies, personalities and life circumstances, all of which interact with the neurological impairment. For Kitwood, 'personhood' or the sense of self-identity or self-esteem is maintained by relationships and is the responsibility of those who are cognitively intact. Fostering 'personhood' becomes central to dementia care (Kitwood and Bredin 1992). The adequacy of the empirical basis of this philosophy of care has however been questioned (Adams 1996).

The cornerstones of therapeutic social dementia care – reminiscence and validation therapy – have in common their acknowledgement of the sense of self of the person with dementia. Reminiscence work and validation therapy acknowledge the importance of affirming the subjective, inner world of the individual. Reminiscence uses a variety of aids to prompt autobiographical memories and affirm the sense of

self (Gibson 1994). Validation therapy is an approach to communicating with and understanding the person with dementia by affirming her or his sense of reality (Feil 1982). It assumes that the individual's behaviour and speech has an underlying meaning.

There is growing empirical research which affirms that people with dementia retain a sense of self despite cognitive impairment. Mills and Coleman (1994), using counselling skills and reminiscence work, present case study evidence that personal awareness of an individual self remains. 'Dementia may fragment the personality of the sufferer, but the personal awareness of individual uniqueness of being remains until death' (Mills and Coleman 1994: 213). Sabat and Harré (1992) present an account of the construction and deconstruction of self through the late stages of Alzheimer's disease. Based on interviews with and observations of three people with dementia, they argue that one's private sense of self persists into the late stages of the illness, and that the loss of self commonly attributed to the disease process is the loss of the public or social self, which they attribute to how others respond to and treat the person with dementia. Their research provides some empirical basis for the less empirically-based assertions of Kitwood (Adams 1996).

The person's rights

There is a growing acknowledgement that people with dementia have rights. This trend towards an emphasis upon autonomy in discussions about dementia is best illustrated by two topics: sharing the diagnosis of dementia, and seeking consent from individuals.

Sharing the diagnosis

The debate about the desirability of disclosing or withholding the diagnosis of dementia is growing as more people are diagnosed at earlier stages of dementia (Drickamer and Lachs 1993; Fortinsky *et al.* 1995; Woods 1995). This trend will be encouraged by recent advances in drug treatments which are effective in the early stages. In general, a diagnosis is disclosed to the family carer(s) but withheld from the person with dementia. A survey of old-age psychiatrists suggests that while family carers have almost always been told the diagnosis, there has been substantial variability in the disclosure of the diagnosis to people with mild dementia, while people with severe dementia have

almost never been told (Rice and Warner 1994). A more recent survey of geriatricians found similar results (Rice *et al.* 1997).

Drickamer and Lachs (1992), drawing on their clinical experience, have summarised the reasons both for withholding and for disclosing the diagnosis. The reasons for sharing the diagnosis include: respect for the autonomy of people with dementia and the person's right to know; and their ability to plan for the future with respect to both health care and finances. Reasons for withholding the diagnosis include: its uncertainty and the variability of the prognosis; the absence of any medical treatment; its potential to cause distress; the inability on the part of the person with dementia to understand the implications; the person's inability to cope with knowing; and family members not wanting their relative to know.

Professional opinion, as reflected in a recent *British Medical Journal* editorial and letters page, suggests that the medical profession is increasingly in favour of diagnosis disclosure being patient-led. While acknowledging the need for further debate, there is general agreement that people with mild dementia should be given sufficient information with which to understand their diagnosis and prognosis (Rice *et al.* 1997) unless withholding such information would prevent harm (Meyers 1997). Maguire *et al.* (1996) suggest that clinicians need to decide between respecting the family's wishes for withholding the diagnosis or respecting the individual autonomy of the people with dementia by involving them in their own care. They found that 83 of 100 family carers did not want their relative to be told about the diagnosis of dementia, even though 71 of them wanted to be told if the diagnosis applied to them. The little research on the topic suggests that people with dementia who have been told their diagnosis are less troubled by their symptoms than those from whom the diagnosis has been withheld. Gilliard's (1995) interviews with nine people with dementia who had been told their diagnosis provide useful insights into the effects of sharing the diagnosis. She argues that the provision of a diagnosis helps people with dementia make sense of what is happening to them. Clearly more research is needed to examine the preferences of people with dementia and the effects of disclosing the diagnosis directly to them (Meyers 1997).

Seeking consent

Central to the principle of autonomy is the requirement that consent be provided for any interventions or treatment. A growing literature is addressing issues of competence and consent in dementia services and

research. There is a general consensus that a diagnosis of a dementing illness does not presume incompetence (Dubler 1985). Post *et al.* (1994) recommended that capacity is a more useful concept than competence, and Brody (1993) refined the principle when asserting the need for differentiation of *task-specific* and *global* capacity. For example, a person's inability to handle finances should not be used as a reason to omit them from discussions about where they want to live.

The literature is equivocal regarding the ability of people with advanced dementia to be involved in decision-making. While some authors suggest the need for preventive measures, such as appointing a Power of Attorney and establishing a Living Will (*e.g.* McCullough *et al.* 1995), others suggest that non-verbal signs can and should inform about the wishes of people with dementia (Berghmans and Ter-Meulen 1995). Berghmans has recently warned against relying on the principle of 'substituted judgement' with respect to end-of-life decisions. Basing decisions on the 'presumed wishes of the former self of the patient, may be a sign of disrespect towards the interest and experiences of "the demented self" of the patient' (Berghmans 1997: 285). The potential for conflict in decision-making between people with dementia and their families will no doubt receive growing attention in coming years (Wetle 1995).

Attention to the perspectives of people with dementia

The former neglect of the experience and perspective of family carers within dementia research led Zarit and colleagues to refer to family carers as the 'hidden victims' (Zarit *et al.* 1985). Subsequently Lyman (1989) and most recently Woods (1997) have argued that people with dementia are the 'hidden victims', not because of the effect of the disease but because their experience of the disease is ignored. Cotrell and Schulz (1993) have challenged the academic community to see people with dementia not as objects but as uniquely situated to help us better to understand the illness and its treatment. They have challenged us to elicit the views of people with dementia regarding their illness and care. They cogently argue for the perspective of the person with dementia to be included in both research and services' design and evaluation. They point out that our neglect of the perspective of the person with dementia has limited our understanding of the variability of its expression. Woods (1997) has recently echoed this call in Britain.

To date most of our understanding about the experience of dementia comes from people in the early stages (Keady 1996). At least three

books have been written by people with dementia which document their experiences (Davis 1989; Friel-McGowin 1993; Rose 1996). These books, all written by people living in the United States, suggest that in the early stages people are acutely aware of their failing cognitive capacity and experience embarrassment, frustration and anger. Friel-McGowin (1993) illustrates too the resourcefulness of people in the early stages of dementia: 'It struck me that while I may forget relatives, co-workers, or the way to the restroom, I certainly found I could think fast enough when cornered, and come forth with a believable bluff' (Friel-McGowin 1993: 20). Ronald Reagan, the former President of the United States, is perhaps the most famous person to have described what living with dementia meant to himself and to his family in the period shortly after being diagnosed with Alzheimer's disease in November 1994. Research which has set out to elicit the views and experiences of people with dementia has been primarily concerned with: (1) how people with dementia cope in the early stages, and (2) their perspective as service users. All have restricted their sample to people in the early stages of dementia.

The experience of early dementia

Most of the studies which elicit the perspective of people with dementia have been concerned with the early stages, in particular their experience of and response to symptoms (Bahro *et al.* 1994; Bates 1994; Cohen *et al.* 1985; Downs and Goldsmith 1994; Gilliard 1995; Keady and Nolan 1994; Keady *et al.* 1995). On the basis of interviews with people with dementia, Cohen *et al.* (1985) proposed six phases through which a person passes as they react to the losses associated with the condition: recognition and concern, denial, anger/guilt/sadness, coping, maturation, and separation from self. Bahro *et al.* (1994), based on their clinical experience and interviews with seven people in the early stages of dementia, concluded that people use a variety of coping mechanisms and that the majority included denial.

Keady and Nolan (1994) exemplify how talking to people with dementia can improve our understanding of the experience of the disease. Based on interviews with family carers and on their own practice experience, they propose that the early experience of dementia involved six stages. Following interviews with ten people with the early signs of dementia, they revised their last stage from 'surviving' to 'maximising'. They also developed the 'Index for Managing Memory Loss' (IMMEL) as an assessment tool for clinical practice. Maximising, they argued, better reflected the creative resourcefulness

that people with dementia had described during the interviews (Keady and Nolan 1995*a*, 1995*b*).

Support groups for people in the early stages of dementia have recently emerged (LaBarge and Trtanj 1995; Snyder *et al.* 1995; Yale 1991, 1994, 1995), mostly in the United States. Support group sessions focus on coping with memory problems, daily living, self-esteem, relationships, health, and legal and financial concerns. Preliminary findings from an evaluation endorse the feasibility of conducting such groups with people in the early stages (Snyder *et al.* 1995). These groups provide another avenue for learning about the early experience of dementia.

People with dementia as service users

A small unpublished pilot study of the perspectives of people with dementia on their use of services was conducted by Sperlinger and McAuslane (1994). The study relied on interviews with six people in the early stages of dementia and concluded that the respondents were reliable informants about both their lives and their service experience. Downs and Goldsmith (1994) interviewed five people in the early stages of dementia regarding their views on services. The study's findings suggest that the conventional semi-structured interview format may not always be appropriate. As Kitwood (1997) suggests, noting what people say in the course of their day-to-day lives may be a useful approach. For example, while having a cup of tea with other people at home-based day care, one of the study participants spontaneously described a recent stay in a 'hotel': "I didn't know anyone there, if only I could have taken a friend with me... There were a lot of people I didn't know. I'd have preferred to be at home with the newspapers". Later, in conversation with the volunteer, it emerged that this was a comment about a recent experience in residential respite care (Downs and Goldsmith 1994).

By combining data from their previous studies, Keady and Gilliard (forthcoming) have found that following diagnosis, people with dementia want a range of information about its effects, about what to expect during diagnostic assessment; about services and supports; and about adjusting to dependency in the caring relationship. They also want reassurance. Barnett (1996) has recently adopted a client perspective, using both interviews and observation, in her evaluation of a purpose-built facility for people with dementia. The study demonstrates the feasibility of eliciting the perspective of people with dementia and the benefits of this approach for maximising service effectiveness.

Several books have aimed to improve communication between carers and people with dementia (Goldsmith 1996; Stokes and Goudie 1990). It has been acknowledged that training in such skills will be required for staff to ensure that the preferences of people with dementia are heard (Bourgeois 1991; Post *et al.* 1994). Killick's (1994) work in long-stay care environments provides an example of one such approach. More research, perhaps using some of the methods described by Kitwood (1997), is needed to explore the experience and perspective of people in the later stages of dementia. Indeed, as Woods (1997: 12) points out, future research will be concerned with devising appropriate research methods 'to identify reliably the fragments of meaning and affect that undoubtedly remain'.

Summary and future research

This discussion has highlighted a growing trend in dementia research: to giving importance and value to the *person* with dementia. In recent years, literature has emerged which acknowledges the individual's experience, rights and perspective. This literature expands our sense of dementia beyond neurobiology and neuropsychology and includes the person's experience alongside the family's. Three themes reflect this changing emphasis, the individual's sense-of-self, the person's rights, and recognition of the value of the perspectives of people with dementia. Recent publications suggest that the individual's sense-of-self persists throughout the disease. Future research may explore how different physical and social contexts affect this sense. There is also a clear trend toward acknowledging the rights of people with dementia, both to information about their diagnosis and to consent to treatment (and research). A great deal remains to be learnt in both areas. The perspectives of individuals with dementia are no longer neglected but there is a clear bias towards eliciting views from people in the early stages. Ideally, further research should redress this imbalance. The growing emphasis on the *individual* with dementia is perhaps best reflected in our choice of language (Woods 1997). It will be interesting to see how the terminology of dementia research in coming years reflects the growing centrality of experiential perspectives. Currently a considerable amount of much published work has described *dementia sufferers* and *dementia victims*, and both the *burden* of caring and the view of family carers as *victims* have been common usage. The coming years may see more use of terms such as *care recipient* and *service user* when referring to individuals with dementia.

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