



Dementia Studies

A Social Science Perspective

Anthea Innes



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CONTENTS

List of Figures	vi
Acknowledgements	vii
1 What is dementia? Unpicking what is 'known'	1
2 The context of dementia studies: political, economic and social issues	27
3 Caring for people with dementia: utopian ideals?	45
4 Dementia studies within cultural contexts	72
5 Researching dementia and dementia care: implications of the generation of research knowledge for policy, practice and approaches to research	102
6 A model for dementia studies: knowledge generation and development	133
References	165
Index	189

LIST OF FIGURES

6.1 A learning cycle – adapted from Kolb, 1984	138
6.2 Applying the notion of a cyclical process for the study of dementia	139
6.3 A model for studying dementia	140
6.4 A web of understanding about dementia – from a medical viewpoint	146

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WHAT IS DEMENTIA? UNPICKING WHAT IS 'KNOWN'

■ ■ Chapter summary ■

- This chapter begins by charting the academic study of dementia from a social science perspective, highlighting biomedical, social-psychological and social-gerontological contributions to a subject that has gained rapid momentum in the last decade.
- Biomedical approaches tend to adopt stage theories of dementia, focusing on a general progressive decline consisting of increases in cognitive impairment and decreasing ability to complete tasks of daily living.
- Social-psychological, or psycho-social approaches (Kitwood, 1997; Sabat and Harré, 1992), provide an opportunity to refocus on the personhood or self of each individual with dementia, and provide the theoretical basis for person-centred approaches to dementia care. The difficulty of defining and ultimately attaining person-centred care has been documented (Brooker, 2004; McCormack, 2004), highlighting the limitations of achieving this in day-to-day care practices.
- Wider issues highlighted by social-gerontological work of the lack of consideration of the implications of the biomedicalization of ageing (Kaufman et al., 2004) and the low status of older people despite their heterogeneity (Dressel et al., 1997) also provide context to the study of dementia. Social gerontology has done much to contribute to the deconstruction of dementia (Harding and Palfrey, 1997; Lyman, 1989; Bond, 1992) and to help question what is 'known' about dementia and thus has implications for the delivery of dementia care services, a topic we will revisit throughout this book.
- This chapter presents an overview and critique of these three approaches, and as such provides a framework and the theoretical foundations underpinning the subsequent chapters in the book.

Introduction

This book approaches the subject of dementia studies from a social science perspective. Two conceptual frameworks underpin the

discussion of what 'dementia studies' entails: the sociology of health and illness and the sociology of knowledge. As the book progresses, the contradictions, paradoxes and multiple interpretations and representations surrounding dementia and dementia care provision will be demonstrated. This all occurs within a specific social context, or what Gubrium (1986) has termed the 'cultural space' of dementia at any given moment in time. Holstein has argued that a worthwhile pursuit for the twenty-first century is to reflect on the relationship between culture and understandings of disease and how understandings of disease tell us about culture and how cultures can provide insights into constructions of disease (Holstein, 2000: 177). This reflects the concern of Harding and Palfrey (1997) in thinking about a 'sociology of dementia' as one whereby the 'facts' of dementia are critiqued and challenged to enable the current dominance of biomedically informed care regimes to be examined and explored.

The following questions have been used as heuristic devices and guide this book:

- What do we know about dementia?
- How do we know what we know about dementia?
- Where does the knowledge we have come from?
- What do we do with the knowledge in policy/practice/research situations?

This chapter does not present a 'theory of dementia' or a 'theory of dementia care', rather it explores and critiques issues and concepts that have emerged from biomedical, social-psychological and social-gerontological thinking. As such, this chapter offers the reader an opportunity to reflect on the underlying assumptions surrounding dementia and dementia care.

Starting points for social science

A concern with concepts of social justice, equality, citizenship and equity has long been the preserve of social science, arrived at from methodologically diverse starting points. Going back to Becker's (1967) classic question 'Whose side are we on?' is an interesting place to begin this chapter, even if it is a slightly simplistic one, where theoretical groundings of our knowledge about dementia are

questioned, and their implications for dementia care practice, policy and research explored in later chapters.

Dementia could be understood as a chronic illness and as such the dominant approaches within sociology to understand illness are relevant. Two approaches are evident in the sociology of health and illness; socio-structural approaches which come under the umbrella of structural functionalists (who look at the impact of an illness for the individual, their family and their day-to-day lives); or interactionist perspectives (which look at the meanings the illness has for the individual and their family and the impact on their identity and sense of self) (Kelly and Field, 1998).

What is similar in sociological approaches to understanding health and illness is the assumption that illness is the antithesis of the norm and ideal of a healthy mind and body and brings with it associations of dysfunction and deviance. When studying health and illness, a popular approach has been to explore how behaviours have been defined as medical problems, thereby giving the medical profession authority to control such behaviour through medical treatments. This is known as the medicalization of illness in the sociology of health and illness literature and first gained popularity in the 1970s and 1980s (for examples see Zola, 1972; Conrad, 1975; Estes and Binney, 1989).

Another common theme identified within the sociology of health and illness literature in the last two decades is the emergence of the 'knowledgeable patient' (Prior, 2003: 41) who can contribute to challenging medical knowledge about disease and illness (as well as confirm it by focusing on experienced symptoms). Thus, the dementia field can be seen to reflect broader health and illness concerns where the views of the patient have become more apparent, reflecting a concern to see the person with dementia in research (Downs, 1997) and care practice (Kitwood, 1997).

So how can these selective social science concerns be applied to unpacking popular knowledge about dementia? We will begin by looking at the medicalization of dementia and the challenges to this medical discourse by social scientists and others who have demonstrated that the construction of dementia symptoms as a 'disease' was a way to make understandable the symptoms of dementia which challenge the social order of acceptable and understandable 'normal' behaviour.

The medicalization of dementia – a brief history

Dementia is a condition, or more accurately an umbrella term for a range of conditions, which has attracted much attention in the 100 years since the work of Alois Alzheimer, leading to the label 'Alzheimer's disease' being applied to individuals. Commonly cited definitions of dementia highlight its construction as a biomedical disease and the accompanying degeneration and loss of abilities over time:

Alzheimer's disease is a degenerative brain syndrome characterized by a progressive decline in memory, thinking, comprehension, calculation, language, learning capacity and judgement. (World Health Organization, 2001)

The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions, including Alzheimer's disease, stroke and many other rarer conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding. (Alzheimer's Society, 2006)

Such definitions succinctly capture generations of health professionals, families and the person with dementia's experiences of cognitive difficulties and decline. What such definitions hide is the knowledge generation process that underpins such statements, which is arguably partial, flawed and incomplete.

A brief 'dig' into the history of one particular form of dementia, Alzheimer's disease, gives an early indication that knowledge about dementia is not as straightforward, nor as consensual, as such definitions may first appear; and that this has been the case since the time of Alois Alzheimer, a century ago.

Histories of the development of Alzheimer's disease highlight the change in focus over time of those concerned with dementia. Holstein (1997) charts the progression of understandings about Alzheimer's disease and senile dementia between 1885 and 1920, and thus includes the 20 years prior to the time when Alzheimer described a patient whose symptoms began with memory loss and disorientation. Through this history, Holstein (1997: 2) provides a direct challenge to what is commonly believed or 'known' about dementia and Alzheimer's disease; highlighting that the language used and symptoms described do not necessarily date back to the origins of the disease label, as may often be assumed. Thus, since the beginning of the twentieth century, it can be demonstrated that Alzheimer's disease,

senility and senile dementia have attracted different degrees of attention over time (Dillman, 2000), and that various factors have influenced the direction that knowledge about dementia has taken. For example, Dillman (2000) highlights various phases in the generation of knowledge, beginning with Kraepelin's concepts of disease, psychiatry and Alzheimer's disease, through to specific pathogenetic theories, leading eventually to the introduction of cholinergic drugs to treat those with Alzheimer's disease. Thus, the production of knowledge and its resultant usage in practice will influence the treatments that those with dementia will be offered.

What Dillman successfully alerts us to is that elements of what is known and believed in contemporary times can be traced back to the early twentieth century, despite Alzheimer himself expressing doubts about the way in which others were using his description of his patient 'Mrs Auguste D' to describe and categorize others with similar symptoms (Dillman, 2000: 135–6). As Holstein explains, by the 1920s, the dilemma of separating pathology from normalcy in old age had not been resolved (1997: 10), leaving a dilemma for those following in the footsteps of Alzheimer, including those working in contemporary times. This legacy has resulted in limiting the focus of enquiry to the neurobiology or neuropsychology of the person with dementia (Cotrell and Schultz, 1993) rather than to the influence of the wider psychosocial context where the individual with dementia is located.

In a convincing critique of the biomedical model and a strong advocacy for including social factors in the study of dementia, Lyman (1989) similarly demonstrates that medical sociologists and social gerontologists had little interest in dementia in the 1980s, with much literature accepting the medical dictates of stages of the disease, the inevitability of a 'social death' and using the medical model as a way to try to understand and control experiences that were often difficult to understand and control. Thus, the medical model was used to legitimize treatments and control of people with dementia through the use of physical or chemical restraints, despite the widespread acceptance that there was no cure (Lyman, 1989: 599). This, Lyman argues (1989: 598), is an example of the 'medicalization of deviance', where behaviour that is difficult to comprehend is 'explained by pathological conditions of somatic origin subject to treatment by medical authority'. Bond (1992), in his discussion of the medicalization of dementia, selects four unfavourable aspects of this process: expert control, social control, individualization of

behaviour and depoliticization of behaviour. Expert control of diagnosis and treatment has led dementia to be the preserve of the medical profession; while social control has been exercised through the use of diagnosis itself which categorizes a person as having a dementia and the resultant treatment and care they may receive. Seeing deviant behaviour in individualized terms keeps a firm focus on the individual diagnosed rather than considering the response of society to such behaviour. Finally, the depoliticization of behaviour involves defining behaviour and interactions through a medical lens rather than looking at the meanings the person with dementia attributes to their situation and their subsequent reaction (Bond, 1992: 400).

Recent histories of the Alzheimer movement (Fox, 1989; 2000) provide the cultural context for the growing public interest in Alzheimer's disease and the corresponding increase in funding made available to biomedical research to investigate causes and cures for dementia. However, Fox (2000) highlights that the very success of the Alzheimer movement in the US in attracting government attention, public interest and funding for biomedical research and thus in tackling the economic burden predicted to increase in the future (2000: 223), has also led to a paradox, in that interest in the ongoing care for people with dementia has not similarly blossomed. Thus, until biomedical research finds a 'cure' for the so-called 'disease of the century', so tantalizingly suggested by the introduction of the 'anti-dementia drugs' in the 1990s, the care for people with dementia is relegated to a second place by funders of research. This is not to suggest that policy makers and funders of research are not concerned about the care of people with dementia today but are constrained by the more politically gripping agenda of a cure for tomorrow.

It is interesting to note the continued dominance of medical knowledge when attempting to explain and understand health and illness. Dementia provides a specific example of a label applied to a set of symptoms resulting in the labelling of people with such symptoms as having an illness or disease, typified by the term 'Alzheimer's disease'. Ticehurst (2001), when addressing the question 'Is Dementia a mental illness?', concludes that dementia has seen a departure from a mental illness to a disease category, and with this move come changes in the way people with dementia will be cared for and by whom. Using psychiatry and mental health legislation to illustrate the changes that have occurred in conceptualizing dementia, Ticehurst demonstrates

that this has an impact on specialisms within the medical profession. Thus, even within medicine and among those working within a broadly medical model of care, there are tensions around who should be providing the care to people with dementia, a tension argued to be a result of outdated mind/body, disease/illness conceptualization of dementia held within medicine (Ticehurst, 2001: 716). Szasz's assertion, 'I hold that psychiatric interventions are directed at moral, not medical problems' (1974: xi), clearly demonstrates the challenge that social scientists have raised to draw attention to the links between the 'objective facts' medicine would have us believe in, and the influence of cultural norms and beliefs and the need to uphold some kind of (moral) order when faced with behaviour that is not acceptable to the majority population.

Indeed, using insights from the sociology of the body, it has been argued that 'society needs dementia to be medicalized, as, if it is classified as a disease, it holds out the prospect of a cure for ageing and for death' (Harding and Palfrey, 1997: 139). While Lyman suggests that viewing dementia as a biomedical condition helps bring order to dementia care (1989: 599). Thus, viewing dementia as a disease brings a legitimacy to the care offered to people with dementia and offers those who are not diagnosed with dementia the opportunity to believe in a cure and that dementia will not be their own individual destiny. Charting developments in the sociology of health and illness between 1979 and 2002, Prior uses Alzheimer's disease as one example of a condition which has developed a lay expertise. She demonstrates that carers' and patients' knowledge of their condition is partial and restricted, with the surface symptoms of the condition being of primary concern to laypeople (2003: 49), reflecting back in much the same way that treatment of symptoms is the primary concern of medicine.

Thus, it is apparent that the dominant medical model is open to critique and challenge, yet despite such challenges this approach remains dominant in discourse surrounding dementia and dementia care. What then are the alternative ways that have been advanced to understand dementia?

The construction of dementia

Through the above discussion of the medical model of dementia I would argue that the greatest contribution social scientists

(Gubrium, 1986; Lyman, 1989; Bond, 1992) have made to the study of dementia is through their deconstruction of the previously held views about dementia which the medical profession offered, and thus that dementia has been socially constructed as a disease or illness to meet society's prevailing concern for order and control. This issue will be apparent throughout the book when we explore, for example, the way in which many people with dementia are removed from their communities and placed in institutional care (discussed in Chapters 3 and 4) and the opposition to hearing the views of people with dementia in research (discussed in Chapter 5).

In the 1980s, Gubrium (1986: 52) was among the first to begin questioning the medicalization of dementia; in particular, he took issue with the terms 'senile dementia' and 'Alzheimer's disease' and the assumption that dementia is a normal part of ageing. Taking an historical look at developments in knowledge about dementia, senility and Alzheimer's disease over time, he concluded that dementia is not an extreme form of normal ageing, but that those with dementia are experiencing a disease that is distinct from normal ageing. Anglo-Americans unified the terms senile dementia and Alzheimer's disease into a distinct disease category in the 1970s and 1980s (Fox, 1989), and as an illness category and policy issue in the 1980s (Lyman 1989). Turning the condition into a disease matters (Holstein, 2000: 171), as this implies that action can be taken, and that both cause and cure can be sought and, further, indirectly constructing a condition as a disease 'contributed to the construction of careers, the instruction of students and the politicization of AD' (Holstein, 2000: 172). Thus, when a person is labelled in a certain way, it impacts on the 'career' (Goffman, 1991) of the person so diagnosed.

The nature of the social construction of dementia has been aptly questioned (Harding and Palfrey, 1997), with Gubrium (1986) clearly setting out the context for commonly held beliefs about Alzheimer's disease which stem from the concerns and agendas of those contributing to what is known about dementia, and Alzheimer's disease in particular. Gubrium presents the backdrop of medical concerns between old age and senility which over time led to the development of diagnostic screening tests relying on the input from family experiences and the presentation of symptoms from the person who may eventually be labelled as having 'Alzheimer's disease'.

Gubrium (1986) charts the development of interest in Alzheimer's disease to the point that Alzheimer's disease is part of 'public culture', where well-known public figures are used to advocate on behalf of carers and those afflicted with the 'disease' to a point where alarm stories emerge, focusing on: demographics (more people having this disease); finances (the financial burden of caring for people with dementia); and personal implications (loss of abilities leading to the removal of the pre-dementia self replaced by the physical shell of a person).

In a text targeted at care professionals, Gubrium (1991) clearly highlights the different interpretations that can be placed on and by older people, with dementia a term that can be applied to those who do not conform to the norms expected by others. In the first chapter of his book, *The Mosaic of Care*, he draws attention to the different interpretations various individuals place on events and the difficulty for staff when a social worker collects conflicting accounts of a situation. The questions posed are: Can the man's actions be understood to be part of his dementia? Or could they be understood to be part of his strategy to challenge the control of the care setting exerted by the woman bathing him? Thus, behaviours can be understood as part of 'dementia' and thus contribute to the construction of understandings about dementia.

These later insights into the construction of dementia as a disease come from a position begun by the medical profession, a position where symptoms arising from neurological impairment were medicalized and problematized. Such labelling of problem behaviours is not just for professionals but used by other older people. For example, Gubrium (1991) describes situations where individual residents can be labelled as 'losing their marbles' (inaccurately) by other residents should the personal characteristics of individuals not be appreciated by others. Gubrium (1991) further highlights the complexity of interpreting the realities of those deemed to be in need of 'care', whether in institutions, in the community (at day care) or care within their own home. An interesting concept of the 'demented role' has been used to allude to Parsons's (1951) 'sick role' (Golander and Raz, 1996). The notion of those with dementia taking on a 'demented role' legitimizes their behaviours that have been labelled difficult in some way and complies with medical definitions of disease and the deviation from the healthy or non-demented role of others. Thus, individuals can be seen to comply with constructions of

roles and behaviours and the meaning that others attribute to actions that deviate from the expected norm. This is problematic, as it further strengthens the preserve of medical and health professionals by dismissing what may be attempts, for example, to communicate by the person with dementia. Rather than look below surface at service provision inadequacies or staffing issues, the 'blame' can be laid at the door of the person who has dementia.

Harding and Palfrey (1997) systematically challenge what is known about dementia through the theoretical framework of social constructionism. In common with Gubrium (1986), they demonstrate that dementia has been equated with old age. While Gubrium concludes that dementia is 'an entity distinct from ageing' (1986: 201), Harding and Palfrey, (1997) suggest that the conceptualization of dementia used within Western societies binds dementia to old age, and the fear of ageing, disease and death that is associated with an ageing body.

The contributions from social scientists to challenge what is known about dementia have yet to receive mainstream recognition, with due consideration about what this may mean for common care practices where people with dementia are institutionalized when a decision is reached that their behaviours are no longer manageable within the community. This is not to deny that people with dementia require long-term care if they decline physically and become unable to maintain activities of daily living, but to highlight that people with dementia may be institutionalized because their behaviours challenge the norms expected within their families and wider communities.

Yet, individuals with dementia and their families are a heterogeneous grouping linked by symptoms associated with dementia, and differences in backgrounds along the lines of class, race, ethnicity and gender (Hulko, 2004) are not always taken into account when providing care solutions to symptoms that are difficult to control. Interestingly, Vittoria (1998) suggests that institutional care can actually help people with dementia preserve their sense of well-being, as it can offer a safe and controlled environment where staff are equipped (some better than others) to help maintain and reinforce the preferred reality of an individual with dementia. McColgan (2001), by contrast, provides a shocking account of the lack of opportunities offered to those living in institutional settings, and thus demonstrates the order and control function of institutional living for those who are labelled

as having dementia. Cultures of care in institutions is an issue we return to in Chapter 4.

Social psychology – the loss and preservation of self or personhood of people with dementia

Arguably, the most important contribution social psychologists have made to the study of dementia and the care offered to people with dementia is to place *the individual* with dementia at the centre of academic and practice discourses. Social psychologists have clearly demonstrated that biomedical views have overshadowed the individual who is given the diagnosis of a dementia (Kitwood, 1997; Sabat, 2001) and that this can, and does have, disastrous outcomes for the individual with dementia.

On both sides of the Atlantic at around about the same time, during the late 1980s and early 1990s, Tom Kitwood (UK) and Steven Sabat (US) both independently began advancing alternative understandings to the decline, decay and deficiency models of dementia commonly espoused by those working within a broadly biomedical approach where dementia was seen as a fate worse than death, and, indeed, texts with such sentiments in their titles were popular at that time (*Alzheimer's Disease: Coping with a Living Death*, Woods, 1989).

Kitwood and personhood

Kitwood (1990) began his challenge to the standard paradigm in 1990 when he first wrote about the dialectics of dementia, highlighting the damage carers could be inflicting on the person with dementia due to careless and thoughtless interactions. He then moved on to begin theorizing about the interpersonal processes involved in caregiving and the impact interactions with caregivers may have on the person with dementia (1993). His thesis on dementia culminated in his book *Dementia Reconsidered: the Person Comes First* (Kitwood, 1997), published shortly before his untimely death. His key contribution to understanding dementia, and in the process challenging the medical model of care, was his insistence that what he termed 'personhood', defined as 'a status or standing bestowed upon one human being, by others, in the context of social relationship and social being. It implies recognition, respect and trust.'

(1997: 8), should be preserved, even if a person received the diagnosis of dementia.

Much of Kitwood's early work was devoted to demonstrating how personhood was eroded by the actions of carers, even if the actions were not maliciously intended, they could still have an adverse impact on what he called the well-being of a person with dementia. 'Malignant Social Psychology' was the term Kitwood used to describe a range of interactions that could be experienced by a person with dementia which were detrimental to their well-being. He called such interactions 'Personal Detractions'; initially, 10 categories were indentified (Kitwood and Bredin, 1992b) but these were later developed into 17 categories of personal detractions (Kitwood, 1997). Such personal detractions could occur at varying levels of severity; mild, moderate, severe and very severe. Mild detractions occurred when no malice was intended, very severe detractions occurred when a caregiver was aware of their actions and the impact they may have on the person with dementia. The final 17 types of personal detractions identified by Kitwood (1997: 46–7) are:

- | | |
|-------------------|--------------------|
| 1 Treachery | 10 Objectification |
| 2 Disempowerment | 11 Ignoring |
| 3 Infantilization | 12 Imposition |
| 4 Intimidation | 13 Withholding |
| 5 Labelling | 14 Accusation |
| 6 Stigmatization | 15 Disruption |
| 7 Outpacing | 16 Mockery |
| 8 Invalidation | 17 Disparagement |
| 9 Banishment | |

The crucial point Kitwood made through these categories of Malignant Social Psychology (MSP) was that an individual would respond when experiencing, for example, a care worker moving them around without explaining what was happening to them, and instead having a conversation with another worker (objectification and ignoring, respectively) and that this could result in a decline in well-being, if not result in ill-being. A full account of how Kitwood operationalized his categories of MSP was one of his first papers challenging the dominant model of understanding dementia (1990), and since then many have used the various categories of personal detractions to illustrate examples of poor care practice observed during research in institutional care settings