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## WHAT IS DEMENTIA? UNPICKING WHAT IS 'KNOWN'

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### ■ ■ Chapter summary ■

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- 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

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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

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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 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

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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 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 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 are posed of 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? 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 rather 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 (Innes and Surr, 2001;

Williams and Rees, 1997; Thompson and Kingson, 2004; Innes and Kelly, 2007).

Kitwood's other primary contribution to the understanding of dementia and dementia care practice was his conceptualization of 'positive person work'. Twelve categories of positive person work are advanced by Kitwood:

- |                 |                                    |
|-----------------|------------------------------------|
| 1 Recognition   | 7 Relaxation                       |
| 2 Negotiation   | 8 Validation                       |
| 3 Collaboration | 9 Holding                          |
| 4 Play          | 10 Facilitation                    |
| 5 Timalation    | 11 Creation                        |
| 6 Celebration   | 12 Giving (Kitwood, 1997: 119–20). |

This framework provided care workers with the opportunity to aim for well-being enhancing interactions in their day-to-day work. Through the use of three specific healing arts therapy techniques used in dementia care, music, dance and art, Kasayka, Hatfield and Innes (2001: 115–20) demonstrate that there are simple steps a worker can take to achieve positive person work and therefore enhance the well-being of people with dementia. For example, to operationalize negotiation in art therapy, a choice of materials can be provided to the person with dementia. For 'creation', that is the opportunity to be creative, to occur during music, singing and group improvisation can be used. Thus, positive person work provided a welcome addition to Kitwood's person-centred care approach; rather than stressing what was wrong with care interactions, he offered caregivers a way to enhance their caregiving skills and thus enhance the personhood of individuals with dementia they worked with.

### Sabat and the self

Sabat's work also focuses on the individual with dementia. The central concern of his work is to stress that aspects of self remain, even for those who are labelled as having 'severe' or 'advanced' dementia. He initially proposed a twofold approach to the self of individuals with dementia (Sabat and Harré, 1992), and later developed this into a threefold categorization of self (Sabat and Collins, 1999; Sabat, 2002). Thus, Sabat argues that there are three forms of self; the attributes of each form of self can be summarized as follows:

- Self 1: this is the singular self and uses the indexicals of I, me, mine to describe personal attributes. For example, I like that, those belong to me, those are mine.
- Self 2: these aspects of self are the characteristics held by an individual, mental, physical and emotional, and the beliefs the individual holds about these characteristics or attributes. For example, I am good at cooking; or, conversely, I am hopeless at cooking.
- Self 3: this is the publicly presented persona that requires the cooperation of others. For example, the roles and relationships an individual holds; worker, parent and friend.

Using detailed case histories, Sabat has demonstrated that Self 1 can remain even when dementia is considered to be advanced. Self 2 can be enhanced or put down, depending on the situation in which a person with dementia may find themselves. Sabat provides examples of individuals in day care choosing not to participate in activities they deem inappropriate to their previous abilities and interests and thus demonstrating a clear sense of Self 2 and Self 3. Thus, choosing not to engage in certain activities may indicate a strong sense of self and not the lack of ability to perform a task or activity. The most vulnerable or fragile self Sabat suggests is Self 3 (2006), which he suggests requires skilled caregiving and interactions to uphold previous relationships and roles.

Sabat applies his concern for recognition of the self when he also questions the use of neuropsychological tests to reveal the incapacity or incompetence of a person with dementia, rather than observing and getting to know an individual to help ascertain the meaning-making behind behaviours attributed as symptoms of dementia (2005: 1031). He also highlights the legal implications of power of attorney and guardianship when tests 'conclude' that a person does not have the ability to construct meaning (2005: 1033). Sabat thus continues to challenge the way in which medical discourse dominates dementia studies and applies his theoretical conceptualizations of self to practice situations.

### **Kitwood and Sabat – some interesting parallels**

Interestingly, Sabat (1994) applied Kitwood's Malignant Social Psychology (MSP) to case studies of individuals with Alzheimer's disease. By following this approach, he highlights that the excess disability attributed to people with dementia combined with the

malignant social psychology that can be experienced by those with dementia by those who provide care (as well as non-carers who do not have dementia) can exacerbate dementia symptoms. It could also be assumed that MSP can encourage professionals to perceive dementia as a progressively disabling disease, as is often observed and recounted by researchers and practitioners (Fontana and Smith, 1989). For example, in common with Fontana and Smith's discussion of the victim of Alzheimer's disease and the 'unbecoming of self' that accompanies the diagnosis of dementia, O'Connor speaks of the two 'victims' of Alzheimer's disease, the person with the diagnosis and their spouse (1993: 113). She argues that the distress experienced by the spouse brought about through observed loss of self in the person with dementia can help to explain the behaviour of spouse caregivers. In making this argument she implicitly accepts that there will be loss of self and that care interactions need to take account of this fact.

In a further application of Kitwood's concepts, this time well-being, to observations of people with dementia, Sabat and Collins (1999) developed Mrs F as a case study. They noted that Kitwood and Bredin's (1992a, b) notions of well-being can be used to recognize intact abilities, feelings and beliefs. Even though initial observations showed that staff found Mrs F very difficult to understand, careful observations over time highlighted intact social, cognitive and emotional abilities, as well as indicators of the well-being proposed by Kitwood. The intact manifestations of self are also demonstrated through this case study, thus providing an example of a synergy between the ideas of two key contributors to the social psychology of dementia, Kitwood and Sabat.

#### What does person-centred care mean for practice?

Kitwood is not without his critics. Davis (2004), for example, although supporting the call for more humane approaches to people with dementia, suggests that 'while ostensibly advocating a personalized and relational approach, he is offering an idea of unimpeachable personhood which sanitizes the dying process (Lawton, 2000)' (2004: 377). Therefore the pseudo-scientific framework Kitwood operates within, whereby the cause of loss of personhood brought about by the effect of MSP implies that changing the interactions and relationships with people with dementia will change experiences of dementia and

in so doing detracts from the challenges that face caregivers to make this a reality for individuals with dementia. Thus, an ideology that is widely accepted and promoted has yet to be tested in reality, and, as Davis has noted, it has not yet been possible to prove or refute Kitwood's hypothesis, but if it is true, then guilt and despair is a possible outcome for carers who cannot achieve the ideal of maintaining personhood.

This may account for the initial reaction of carers to Kitwood's ideas. Capstick has documented (2003) the initial reluctance of carers to accept Kitwood's challenge to the view of dementia prevalent at the time of his first writings about dementia; the language he chose to use was seen to be an attack on the care decisions and care interactions offered to people with dementia. Throughout the 1990s, care interventions became more popular with journals such as the UK-based *Journal of Dementia Care* providing practitioner accounts of success stories when they adopted an approach that could be described as 'person-centred'. The problem with such anecdotal accounts is that they are not based on empirical research; a recognized problem, addressed by an array of psycho-social intervention studies, suggesting, perhaps unsurprisingly, that when an intervention such as music, dance, or art is introduced to people with dementia, then visible signs of well-being increase. Tools to measure the impact of care interventions have also been popular. One devised by Kitwood and Bredin in 1992, 'Dementia Care Mapping', aimed to measure the extent to which the principles of person-centred care, as advanced by Kitwood (1990), were a reality in care settings for people with dementia. This tool is currently in its eighth edition, a result of colleagues from the Bradford Dementia Group and their network of international trainers attempting to address problems with the tool and ensure that the tool could make greater claims to reliability and validity (Brooker and Surr, 2005).

The method, like the theory underlying the person-centred approach, is not without its problems, and a collection of edited papers from practitioners from various countries brings such issues to the fore (Innes, 2003). For example, Müller-Hergl (2003) demonstrates the need for a certain belief system within an organization for Dementia Care Mapping to result in improvements to the care offered, while Scurfield-Walton (2003) provides an example of the need to provide training, mentoring and support to staff to enable them to act on the issues arising from using the Dementia Care



Mapping tool. Even relatively simple steps that could be taken by staff from Dementia Care Mapping, such as revising care plans (Innes, 2003) may be difficult to achieve if the basics of a person-centred philosophy are not understood.

There are two writers who have tried to consolidate and develop what is meant by person-centred care. First, McCormack (2004), writing about person-centred gerontological nursing, argues that although the use of the term person-centred is commonplace, there are few research studies of person-centred practice and even fewer identifying the benefits of this approach to care practice (McCormack, 2004: 31). McCormack concludes that there are four concepts underpinning person-centred nursing: being in relation; being in a social world; being in place; and being with self. He thus brings together the ideas of Kitwood (1997) and Sabat (2001) but with a practice orientation. He argues that person-centred care principles require 'nurses to engage in authentic humanistic caring practices that embrace all forms of knowing and acting, in order to promote choice and partnership in care decision making' (McCormack, 2004: 36). Although McCormack concludes that personhood is a useful ideal to strive for and that person-centred models of care are worthwhile, he points out that care practice needs to be driven with a focus on the individual rather than a focus on theory and models for person-centred care to be a reality in practice. Thus, implicitly the ideas of searching for expressions of the self advocated by Sabat (Sabat and Harre, 1992, Sabat and Collins, 1999, Sabat, 2002, Sabat, 2006), are one way to help focus on the individual, rather than on person-centred principles which could lead to overlooking what, as Sabat has expressed it (2002), 'manifestations of the self remain'.

In a similar, if more pragmatic vein than McCormack (2004), Brooker suggests that person-centred care involves recognizing that 'dementia-ism' (2004: 217) exists in many care settings and that people with dementia are likely to be stigmatized and discriminated against, both strategically and individually. Building on the work of Kitwood, Brooker identifies person-centred care as a combination of four factors: valuing people with dementia and their carers (a theme we will revisit in Chapter 3); treating people as individuals; trying to look at the world from the perspective of the person with dementia; and a positive social environment to enable the person with dementia to experience relative well-being (Brooker, 2004: 216–19). Achieving the ideals of the theoretical approach to dementia set out

by Kitwood is challenging. Brooker highlights that the term person-centred care 'has become a shorthand for encompassing a whole movement in the dementia field' (2004: 221). Thus, the theoretical concepts offered by social psychologists, Kitwood and Sabat in particular, are a beginning and provide a starting point for examining, challenging and changing dementia care practice.

### **Contributions of social psychology to understandings and conceptualisations of dementia**

The last decade has seen a period of intense interest and support for person-centred approaches. Texts advocating care practice similar in perspective to Kitwood's approach have emerged from around the world. In America, for example, there has been a popular text, *Best Friends Approach to Dementia Care* (Bell and Troxel, 2003). Kitwood's work now has widespread appeal, with person-centred care, personhood and well-being phrases commonly used by practitioners in their day-to-day work. The impact, if any, of usage of such language on the care received and the lives of people with dementia is still relatively unknown.

Part of the problem in taking Kitwood's pioneering work forward stems from the lack of working definitions of the terms he uses, and the paradox between Kitwood's ideals and the underlying theory and models of research and disease influencing his work in the dementia field. Harding and Palfrey illustrate that it is difficult to dispute the hypothesis initially put forward by Kitwood and Bredin (1992a) that insensitive care serves to inhibit rementia' – which remains intact because it has neither been proved or disproved. It may therefore take its place alongside the biomedical 'theories', for in many respects it also adopts a positivist view of dementia as a condition, which in some individuals may be treated or even cured (Harding and Palfrey, 1997: 64). Thus, the problematic nature of dementia as a disease category is not fundamentally challenged by Kitwood. He takes issue with the narrow categorization, or 'standard paradigm' as he calls it (1997: 35), based on only neurological impairment and adds dimensions to what the experience of dementia entails, notably social psychology, physical health, life history and biography (Kitwood, 1996) but he does not take issue with the actual categorization of dementia as *a disease*. This can be seen in his belief that dementia can be treated in some way, although he advocates the need for skilled

care practitioners and therapeutic interventions (Kitwood, 1997) rather than the use of psychotropic medications.

That said, symptoms associated with dementia are very real to those who experience them: the person with dementia and those who provide care or services. Advocating the use of sensitive care-giving which enhances life, rather than medications which can lead to individuals being in a semi-awake state and slipping in and out of lucidity, is arguably a more humane approach to the care for people with dementia.

An intriguing possibility is advanced that those with dementia are retreating from the realities of an ageing body; and as they do so, argue Harding and Palfrey, 'that with ageing comes a retreat from the body, and with this retreat comes a loss of sense of self' (1997: 140). Thus, the loss of self, or the difficulty in observing the three aspects of self developed by Sabat, may be compounded by the difficulty individuals with dementia may have in recognizing their ageing body and thus retreating to earlier memories of a healthy, youthful body and mind.

It can be seen that social psychology has contributed much to understanding the experience of dementia at an individual level and the impact dementia may have on the self or personhood of each person so diagnosed. How to operationalize conceptualizations of self and personhood is a challenge for individual care practitioners (we will explore this further in Chapter 3), yet the theoretical foundations are in place to build and develop further our understandings about dementia and dementia care. However, such individualized approaches need to be grounded in an understanding of wider structural forces that shape individuals' experiences for knowledge to develop beyond the individual level. The work of social gerontologists is useful to help achieve an understanding of dementia that takes into account wider social and structural factors that will shape the experience of an individual with dementia.

### **Applicability of wider social-gerontological understandings of being 'old' to the study of dementia**

Old age is surrounded with perceptions which have been called the myths of old age (Sidell, 1995). Such myths include that older people are a homogenous group; that ill health can be expected in old age

(Sidell, 1995: xvi); in turn leading to a commonly held belief that older people are a burden, as they experience such ill health and physical decline. The homogenous grouping of older people together has been robustly challenged (Dressel et al., 1997), with differences along class, gender and race divisions now widely accepted to have an impact on an individual's experience of ageing. It was also commonly assumed that as people live longer, ageing will bring with it a 'burden of dependency' (Walker and Phillipson, 1986: 2). Challenging such a belief has proved problematic when writers describe what has been termed an 'apocalyptic demography' (Robertson, 1990), where the ever-growing number of older people need to be cared for by a shrinking working-age population who provide the tax payments to contribute to providing health and social care services.

This approach to demography has been applied to Alzheimer's disease (Robertson, 1990) and as such has acted as a disincentive to providing care for those with dementia as funders choose to finance research seeking a definitive cause and cure for the condition (Fox, 2000). Thus, beliefs about the burden that will be placed on society due to increasing numbers of people living into old age shape the social world experienced by older people. The interplay between society, image and place provides insights into the complexities and pervasiveness of ageism within Western societies (McHugh, 2003). Older people can be seen to have internalized such ageist messages when they state that they do not wish to be a burden (Hardy et al., 1999; Minichiello et al., 2000) when their views are actively sought.

An approach within social gerontology that is of particular relevance to understanding dementia is that of critical gerontology. Central to the approach of critical gerontology is that ageing is socially constructed (Vincent, 2003). Critical gerontology comes from key principles within four broad approaches concerned with the study of age, sociology, demography, anthropology and political economy (Baars et al., 2006: 5). In a review of the social construction of old age over time, Johnson (2005) demonstrates the variance in ways in which different societies at different moments in time perceive their older people, as such he effectively demonstrates the specificity of constructions of old age and how these reflect social and political concerns at particular points in time. In addition, critical gerontology does much to add to our understandings of the power differentials that older people encounter, for example the unequal distribution of resources said to prompt the emergence of

critical gerontology (Powell, 2001: 120), an issue that has been argued to be of global importance and will influence gerontological theory in the future (Phillipson, 2003: 9). Furthermore, critical gerontology has argued for the need to explore the lives of older people (Walker, 2006), including their identities, and the way in which their experiences are represented (Cohen, 1994), in much the same way that the dementia field has begun to include the views of people with dementia, an issue we will explore in Chapter 5 of this book. This emphasis on the construction of old age parallels the arguments about the social construction of dementia discussed above, as such critical gerontology can be useful in helping to develop understanding about dementia.

Featherstone and Hepworth (1991) were among the first to apply the analogy of a 'mask' to describe the experience of ageing. The concept of a 'mask' has been used by others concerned with ageing experiences (Ballard et al., 2005) and has also been developed and applied to the experience of dementia (Golander and Raz, 1996). The use of the term 'mask of ageing' or 'mask of dementia' demonstrates that individuals who are experiencing old age and dementia are, figuratively speaking, wearing this experience on top of the self (younger, healthier) that the individual wishes to recognize.

Estes and Binney (1989) highlight the problems of the biomedicalization of old age. They describe how old age has been socially constructed as a process of decremental physical decline, 'fostering the tendency to view ageing negatively as a process of inevitable decline, disease and irreversible decay' (1989: 594), and how this has led ageing to be placed in the domain and control of biomedicine. Revisiting the concept of biomedicalization of old age, Kaufman et al. argue that, 'A major effect of biomedicalization today is that the aged body tends to be viewed now as simultaneously a disease entity, a site for restoration and a space for improvement' (2004: 736). They suggest that as increases in medical interventions to prolong life have become available, this places older people and their families under an obligation, rather than a choice, to accept treatments in their efforts to prolong life and avoid the images and reality of demise in old age.

This in turn places family members in a new cycle of caregiving, where care is tied up with medical interventions to prolong life. Kaufman et al. highlight that medical advances prolong life and as such redefine what is considered 'normal' or 'natural' about ageing, which has led to as yet unexplored sociocultural and ethical impacts

of the biomedicalization of ageing (2004: 733). Thus, the biomedicalization of dementia reflects a wider trend in conceptualizations of age and ageing. The advent of anti-dementia drugs fuels the search for prolonging life in the hope that a cure will emerge, reflecting, as Kaufman et al. (2004) point out, the hope that scientific developments have brought to older people and their families.

Dementia also presents an interesting example of the anti-ageing science discussed by Vincent (2006a) where new scientific developments are often viewed as a panacea for ageing and a way to eradicate this final stage in the life course, a position Vincent takes issue with as it continues to see old age as a problem to be resolved rather than a stage of life to be embraced and accepted. The long-term ramifications for society – as attempts are made to grow older without ageing, and to extend life and postpone death – remain unknown, but Kaufman et al. argue (2004: 737) that it is likely that relationships and care provision will have to alter to meet the increased life expectancy of future generations.

Social gerontology, therefore, alerts us to the discrimination faced by older people in Western societies and highlights the cross-cutting interplay of gender, class and age (Dressel et al., 1997) on ageing experiences. Given the ageist social context people with dementia are located within, it is perhaps unsurprising to discover the push towards medicalizing this condition and the avoidance of engaging with the lived realities of people with dementia. Not until the time of Kitwood (1997) and Sabat (2001) was this approach challenged when they suggested alternative ways to conceptualize and then look at the experience of dementia, an experience where the self and personhood of individuals may remain intact in some way, despite the discourse propounding the progressive and irreversible nature of dementia.

## **What is known about dementia? A social science overview**

Medical understandings of dementia have dominated dementia studies discourse for 100 years. Katz (2006) argues for critical gerontology to question the extent to which assessment of functionality as the dominant approach to understanding ageing, similarly those working in the dementia field need to question the conceptualizations of dementia that are based on lack of ability to function due to cognitive impairment. Yet, the foundations of such understandings, from lack of

consensus over medical categorizations to treatments and the never-ending quest for a cause and cure, have perhaps been the key factors influencing social psychologists and social scientists to challenge and contribute to shaping alternative discourses about dementia.

As has been noted:

If medical researchers and practitioners were basing their judgments on firm theory resulting from an extensive body of empirical evidence then their interpretation of dementia as a disease ought to carry more weight. The positivist search for a cause-effect nexus has to be framed within a social and cultural context. This human quest to discern the first cause, to establish a predictable and natural social universe, creates for itself systems of rationality. These in turn produce categories to which experience is allocated: 'Our inheritance is a dichotomized world view in which we attempt from our idiosyncratic beliefs, to reconcile apparent opposites: good-bad; mad-sane; diseased-whole.' (Harding and Palfrey, 1997: 144).

Thus, it is somewhat inevitable that challenges to disease models of dementia would emerge, resulting in alternative ways to approach to care and treatment of people with dementia.

The key contribution of social psychologists and sociologists such as Sabat, Kitwood and Gubrium is that they offer alternative explanations of the lived experiences of dementia to the commonly held pseudo-medical interpretations of loss of self, abilities and meaningful lives. The conceptual difficulties surrounding the term 'dementia' are acknowledged by many but as Post highlights (1995; 2000) there is a moral challenge that remains, no matter what the definition used, and that is to enter the culture of dementia. Kitwood (1997) takes this position further and provides a detailed account of the damage that can be inflicted on a person with dementia should the individuality, or 'personhood', not be maintained. Should no attempts be made to engage with personhood, and should personhood not be maintained, then the process Kitwood (1997) coined 'Malignant Social Psychology (MSP)' occurs where, as a direct result of the actions (even if they are unintentional) the person with dementia may experience, for example:

- Disempowerment
- Invalidation
- Infantilization
- Treachery
- Objectification

Kitwood (1998) and Post (1995) both engage with the 'moral' challenge of dementia, recognizing that dementia poses a challenge to what is desirable within Western cultures, with Post calling for 'moral solidarity' (1995) and Kitwood calling for 'relationship-centred care' which abandons the standard paradigm of understanding dementia and breaking down the barriers between 'us' (without dementia) and 'them' (who have dementia). This is reinforced by Sabat (2001: 340) when he argues that dementia is about us all and how we are as human beings. The fear dementia can promote, due to images of the loss of selfhood so prevalent in the literature, with compelling images conjured up in the titles to publications such as *Coping with a Living Death* (Woods, 1989) and images of carers living through a '36-Hour Day' (Mace and Robins, 2006) and 'The Loss of Self' (Cohen and Eisdorfer, 1986), contributes to statements of dementia being 'the disease of the century'. War analogies, where caregivers 'battle' against the disease and Alzheimer's movements 'fight' for government recognition of the consequences of dementia (Gubrium, 1986), have all contributed to a climate where dementia has been perceived negatively. It is not until later challenges have emerged clearly providing examples of the continuation of aspects of self (Sabat and Harré, 1992; Sabat, 2001, 2006) or 'personhood' (Kitwood and Bredin, 1992a; Kitwood, 1997) that conceptual debates can be circumnavigated to look at the experiences of those directly affected by dementia – the diagnosed and their caregivers.

Vittoria (1999) provides further insights into the lives of people with dementia, where the constructed reality of living in an institution can act as a buffer to the detrimental and degrading views of people with dementia. She aptly demonstrates that the lives of those in long-stay care will be perceived by different people in different ways, depending on the starting point or perspective of any individual, thus echoing Gubrium's position where he provides various scenarios of older people (not just those with dementia) and the interpretations that the individual, different staff members and family members can place on situations. Vittoria's (1999) position in particular challenges the often negative perceptions of dementia care based on other interpretations of institutional life (McColgan, 2004), alerting us to the need to revisit the challenges that have been made to the care of people with dementia, an issue we will return to in Chapter 3.

The dominant medical position is now argued to be that Senile Dementia of the Alzheimer's Type (SDAT) is a disease where exogenous



and endogenous events cause pathological changes in the brain; these may be a result of age-related characteristics but not exclusively (Holstein, 2000: 171). Thus, as outlined above, it is now easy to find challenges to perspectives of dementia solely defined as a 'disease'. However, it should be noted that the above discussion is intended to offer a critique of the knowledge that prevails about dementia in the twenty-first century, a critique of 'what is known' being after all one of the key dimensions social science can bring to the study of dementia.

## Conclusions

Drawing on conceptual frameworks stemming from the sociology of health and illness and sociology of knowledge, this chapter highlights that adopting a social science perspective (of which there are many), can help us to begin to challenge the knowledge and underlying assumptions about what is 'known' about dementia. The flaws inherent in our understandings of dementia can therefore emerge, helping to illuminate the rationale underlying care practices that continue to exist, despite critiques of the starting points of disease labels. The medical approach does, of course, have its place – dementia does, after all, often involve decline over time and causes distress to the person afflicted and their families. By placing too much emphasis on the need for future treatments (medical) and future cure (also medical), there is a regrettable shift away from responding to the care needs of those who have dementia in the here and now.

This chapter has begun to address the first question guiding this book, where does our knowledge about dementia come from? It highlights that assumptions underpinning 'dementia' that go back over a century have not necessarily been consensual concepts, nor have knowledge generation and theories of dementia emerged that encompass the perspectives of all players in the theory generation game. In some ways, developments in the dementia field reflect the further developed movements with in gerontology, where it has been argued that 'despite the valuable and often provocative insights generated by each of these perspectives ... None of these approaches taken alone, provides an adequate paradigm or conceptual basis for theorizing aging' (Baars et al., 2006: 3). Rather, medical dominance remains through the language that is used to describe dementia and

through the responses of society to those who have dementia (an issue we will return to in Chapter 3). However the point made by Vincent (2006b: 268) in relation to gerontology also holds true for the study of dementia:

Processes of social stratification mark some people out by age criteria and institutionalize a set of social positions within which they are required to live out their lives ... A critical analysis is required if we want to find out how such processes happen and how they might be changed.

We will now move forward to consider what we know about the context shaping our knowledge of dementia, and in the process address how we know what we know about the lived realities of people with dementia.

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#### ■ ■ Further reading ■

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For a full account of the principles of person-centred care that are still very much in evidence at the time of writing, read Kitwood (1997); for a similar psychosocial approach but using the concept of self rather than personhood read Sabat (2001). The first critiques (Lyman, 1989; Bond, 1992) of the bio-medical approach provide a useful starting point for thinking about what dementia is and the implications of conceptualizations for those with dementia.