

Researching dementia: are there unique methodological challenges for health services research?

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ABSTRACT

Health services research has been dominated by the biomedical paradigm and positivism, and the funding cultures of biomedicine have dictated the choice of method used by researchers. Social science paradigms, however, have been recognised as increasingly important within health services research and both quantitative and qualitative methods are accepted as appropriate. Older people with dementia have usually been excluded from or marginalised in studies about dementia because of traditional assumptions about the ability or appropriateness of people with dementia to act as participants or respondents. The choice of research method should be driven by theory and not by ideological or political prescription. Theory-driven pluralistic approaches to method will facilitate participation of people with dementia in research through the valuing of personhood. There are no unique methodological challenges in researching dementia. Rather, the complex nature of dementia and dementia care highlight the methodological challenges of investigating complex social phenomena.

KEY WORDS – dementia, health services research, theory, methods..

Introduction

Dementia has probably replaced cancer as the most feared by older people of all modern diseases. From the perspective of public policy, dementia is perceived as the modern epidemic of later life. Contemporary estimates suggest that some 6.6 per cent of people aged 65 or over have dementia (MRC CFAS 1998)¹. These estimates equate to some 550,000 people in England and Wales who would be expected to be experiencing dementia of mild or greater severity. The prevalence of dementia rises markedly with age, the prevalence among people

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aged 65 or over doubling every 5.1 years (Jorm *et al.* 1987). Age has been highlighted as the most important risk factor for dementia (Jorm 1990), suggesting that deterioration in cognitive function may be part of the normal ageing process.

From a clinical perspective, dementia is a label for a behaviour syndrome which covers a range of possible disease states. It is a medical category, defined in social terms as a loss of intellectual power which leads to difficulties in remembering, making decisions, thinking through complex ideas, carrying out practical tasks, retaining information and acquiring new skills. The decline in everyday life competencies is sometimes associated with socially unexpected and often unacceptable behaviour. From personal accounts of formal and informal caregiving and from social research, we know that caregiving can have substantial personal costs (RIS MRC CFAS 1997), but also benefits (RIS MRC CFAS 1998). Society's taken-for-granted assumptions about the impact of the disease on the person with dementia are consistently negative. Our stereotypes of the experience of dementia are fuelled by the alarmist reporting of the tabloid press and by the negative discourse of politicians and policy makers. People experiencing mild symptoms of the condition are often aware they have dementia but there is a strongly held belief that people with dementia are unable to communicate what they are really experiencing. As with death, with a few exceptions (Lorimer 1990), no one has 'returned' to tell us what it is like to have dementia.

It is only comparatively recently that potential medical and pharmacological treatments for the condition have been developed, but recognition of effectiveness is tightly contested (Melzer 1998). In contrast, health and social care interventions have existed for some time but, where effectiveness has been examined, judgements are rarely made through the involvement of the person with dementia, reflecting the dominant positivist paradigm in evaluation research. The traditional scientific paradigm of biomedical and epidemiological research has involved older people with dementia, but in only a limited fashion in the assessment of cognitive function. This approach is characterised by the testing of cognition through memory tests and other psychological devices, and by correlating test results with independent clinical assessments and occasionally some external criteria such as brain biopsies. To describe this as 'participation' is undoubtedly a travesty, since the participant has a limited role as the provider of test material, 'as a passive *vessel of answers*' (Holstein and Gubrium 1995: 7).

The purpose of this paper is threefold. First, to investigate, within the context of the study of dementia, the epistemological basis of the

hegemony of the biomedical model and positivism in health services research, and to consider other approaches to method adopted by anthropologists, sociologists and social psychologists in the study of health and illness. Second, to review critically a range of sociological and social psychological theories relevant to the study of dementia. Third, to contest the view that the study of dementia and dementia care presents unique methodological challenges. We argue that there are no unique methodological challenges in researching dementia or dementia care. Rather the complex nature of dementia and dementia care, like other chronic conditions, highlights the methodological challenges of investigating complex social phenomena.

Health services research

Ownership of health services research as a topic area of study is contested by the different disciplines involved. There is agreement that it is a multidisciplinary enterprise which brings together the social and behavioural sciences, statistics and epidemiology and clinical subjects within primary and secondary care. Traditionally health services research has been under the control of medicine and situated within academic public health, although departments of public and social policy have laid claim to some aspects. With the current policy importance of evidence-based health the topic has become dominated by clinical epidemiologists.

Within the UK, health services research emerged in the early 1970s, supported by the government health departments. A number of multidisciplinary research units were established within Universities to assist policy decision-makers by providing research-based information on the operation and organisation of health and social care. It was also around this time that Cochrane published his extremely influential book on the importance of the randomised clinical controlled trial for the evaluation of health interventions (Cochrane 1972). The central message of this was the need to pursue traditional experimental methods in order to determine the effectiveness of treatments. But to this he added economic theory, arguing that treatments should be not only effective but also efficient, given the societal recognition of the increasing scarcity of health care resources and the increase in demand for health care services. For almost 30 years the randomised controlled trial has remained *the* method of health services research, other approaches to method being sidelined by those disciplines for which experimental method is the only way to 'do science'.

The customer-contractor principle enunciated by a government report on medical science (House of Commons 1971) dominated health services research in the 1970s and 1980s. The key feature of the customer-contractor principle was the political control of science and the suppression of scientific curiosity or imagination. Health services research became a commissioned activity with customers determining research priorities and topics of research. As a consequence, much of the research sponsored by government remained atheoretical and often unco-ordinated. This had considerable impacts on the careers of the researchers involved, who found themselves switching between different topics and developing a knowledge base in a wide range of topics as well as in the other cognate disciplines of health services research.

Following publication of a report on medical research (House of Lords Select Committee on Science and Technology 1988), the environment for health services research experienced further change (Department of Health 1991). There was a reduction in direct contact between policy customers and researchers and a contraction in the number of directly-funded government research units. Government health departments and the NHS Executive started to commission research on specific topics generated through consultation with professionals, users and other stakeholders. Throughout these changes in commissioning practice, the choice of method continued to be the randomised controlled trial.

The biomedical model of research and positivism

Both the biomedical model and positivism are the product of the Enlightenment, an 18th-century movement based on notions of human progress through the application of reason and rationality. The science and humanism of medicine is therefore perceived as largely beneficial and progressive in understanding and responding to illness and disease. The model is based on six assumptions. First, that mind and body can be treated separately. Second, that the body is rather like a machine and can be repaired when it breaks down, although biomedicine has not yet perfected techniques for every breakdown. Third, the impact of this approach is for medicine to assume that there is a technological solution for everything. Fourth, biomedicine is reductionist, explaining disease in biological terms while ignoring psychological and social factors and, fifth, it is assumed that every disease has a specific aetiology. Finally, biomedicine claims to be an objective science and

therefore medicine is the only valid perspective for understanding disease and illness (Atkinson 1988).

Within mainstream health services research, the biomedical model has been supported by positivism. Yet within the social sciences positivism has been the subject of heated debate. Like biomedicine the aim of positivism is to reduce explanations of all phenomena to the smallest number of principles or laws. It was Comte who first articulated the appropriateness of the positive method for all science. It was also Comte who saw positivism as a means to predict social behaviour in order to control it. It is no wonder that a strong antipathy to positivism came from early feminists who saw positivism as the method of the male oppressor (Eichler 1988). A key tenet of positivism is that all scientific knowledge should be acquired in the same manner. As a result, quantitative methods became the substantive approach to method for much of the social sciences and were strongly defended (Popper 1961). This entails a uniform method of data collection which enforces a particular mode of description and classification on the 'reality' being studied. This affinity to the methods of the natural sciences reduces social science to a technical enterprise which has no necessary value implications.

In simple terms, positivism is a circular or spiral process (Wallace 1971). Current knowledge or theory suggests specific hypotheses. Data are collected about operational variables, and hypotheses are then upheld or rejected, depending on the findings. Through this process there is a quest for the smallest number of laws which will explain how things worked in the past and will predict how things will work in the future. In essence, positivism depends principally on being able to challenge predictions set up as hypotheses and on attempting to falsify them. If a prediction fails, the theoretical proposition giving rise to it must be changed to take account of this finding. Any revision of the theoretical concepts and propositions leads to revision of theory and the whole circular process begins again.

Challenges to positivism

The challenge to positivism and the quantitative approach to method, came from a number of directions in social science, from symbolic interactionism, phenomenology and ethnomethodology and, increasingly, from feminism and postmodernism. Phenomenology and ethnomethodology rejected positivism and quantitative methods from a substantially methodological perspective rather than from the

TABLE 1. *Summary statement of central assumptions and criticisms of positivism* (after Atkinson 1978; Bond and Bond 1994)

<i>Positivist assumptions</i>	<i>Criticisms</i>
Social phenomena have an existence external to the individuals who make up a society or social group and can thus be viewed as objective facts in much the same way as natural facts	Social phenomena are of an essentially different order to natural ones, owing to their symbolic nature and the subjective interpretations of social meaning by individuals in society
<i>hence</i> An observer can identify social facts relatively easily and objectively	<i>hence</i> Identifying social phenomena is a very problematic exercise which involves the assumption that an action has a single unchanging meaning for all people, times and situations
<i>hence</i> Numerical and other 'scientific' techniques can be adapted to 'measure' social facts	<i>hence</i> Attempts to 'measure' will gloss over the above problems and lead to the imposition of observers' definitions on to a situation where the extent to which these are shared by actors under study is unknown
<i>hence</i> Hypotheses which relate observer-defined variables can be tested	<i>hence</i> To construct hypotheses is to assume that the problems listed above are either trivial or have been overcome
<i>hence</i> Social theories can be constructed on the basis of discovered 'relationships' or tested by deducing testable hypotheses from some general theoretical statement	<i>hence</i> The bid to explain social phenomena which are seldom adequately described in terms of actor orientations is at best premature and at worst a total misrepresentation of the problem of social reality
<i>hence</i> Social science can proceed with methodologies based on natural science models	<i>hence</i> Social science must develop alternative methodologies appropriate for studying subject matter which poses problems not faced by the subject matter of the natural sciences

theoretical stance of feminism and postmodernism. The earliest challenges to positivism, however, emerged from the symbolic interactionists. The key assumptions of positivism and criticisms are shown in Table 1.

What are the implications for health services research of the challenges to the biomedical model and positivism? Central to this are the research questions being asked and the specific nature of individual study objectives. Much of health services research focuses on the important issues of effectiveness and efficiency and the method of

choice is the randomised controlled trial. For many health technology evaluations this will be the appropriate method but, in using an experimental design, we make a number of assumptions about the 'laboratory' in which experiments are conducted. Within the biomedical model we assume that treatments are homogeneous and delivered under equal conditions. Most treatments investigated by health service researchers are complex and heterogeneous. For example, in the investigation of pharmaceutical agents in animal models within the traditional laboratory we might confidently assume that similar doses are given to animals according to a clear protocol. (Although we would not argue that the quality of the environment does not influence animal welfare and outcome, these are held relatively constant by the random allocation of animals living in the same environment. Similarly we would not argue that occasional unintended lapses to protocol do not occur). But in human populations the context in which experiments are conducted is less well controlled. Individual preferences come into play. The distinction between explanatory and pragmatic models in randomised controlled trials (Schwartz and Lellouch 1967) has been widely used to moderate these challenges.

A key feature of a randomised controlled trial is the clear definition of outcomes, such as death or the specific biomedical markers that might be used in experimental animal studies. Outcomes for human populations are more complex once we move beyond survival. They need to be clinically, psychologically or socially significant. The challenge for health services research is to identify relevant outcomes and to decide how they might be measured. For example, the measurement of participants' perceptions of their quality of life is seen as an increasingly important outcome in many clinical trials. The assessment of quality of life is grounded implicitly in a number of social science theories, but are often neglected by individual researchers using positivist methods when developing measures of quality of life. This traditional approach to the measurement of quality of life ignores the symbolic nature and meaning of life to the individual. It assumes that individual perceptions remain unchanged. Where changes are recognised they are treated technically, for example in terms of 'response shift' (Schwartz and Sprangers 1999). Traditional approaches are grounded in the researchers' definition of the situation, and the extent to which these are shared by participants is unknown because they may be offering public rather than private accounts (Cornwell 1984). The danger of this approach is that we measure the 'wrong' outcomes in clinical trials, outcomes which are not relevant to participants. Individualised approaches to the measurement of quality of life have

been developed to address some of these challenges (O'Boyle *et al.* 1994). The drive to measure the quality of life for people with dementia highlights more vividly these challenges (Bond 1999).

Theory in dementia research

Biomedical theories of the causes and experiences of dementia describe dementia as a 'disease' and as the loss of 'normality'. From a biomedical perspective, dementia and the impact of the condition on family caregivers, can be best understood in terms of 'personal tragedy theory' (Oliver 1986) with people with dementia being labelled as 'victims' or 'sufferers'. Other consequences of this approach for people with dementia has been the individualisation and medicalisation of the 'illness' (Lyman 1989; Bond 1992), processes which lead to blaming the individual and loss of personhood (Kitwood and Bredin 1992b).

Within social and behavioural sciences a range of theoretical perspectives has been used in the study of dementia. Adopting a functionalist perspective, an approach analogous to natural science, early sociologists of health and illness characterised the distinction between illness and disease. Some of the social consequences of illness were explained by role theory (Parsons 1951). From the same perspective, dementia could be described as a form of social deviance, 'conduct that is a violation of the rules constructed by a given society or group' (Berger and Berger 1976).

The symbolic interactionists reconceptualised deviance within labelling theory. The term 'labelling' refers to a social process by which individuals or groups classify the social behaviour of other individuals. Labelling theory identifies two types of deviance: primary and secondary (Lemert 1964). Primary deviance refers to the act of labelling by an actor who is accepted by the wider social group as having the authority to do so. In contemporary society, whether the label 'dementia' or 'demented' has meaning in relation to a particular individual will depend on whether the label has been legitimised by a diagnosis of the condition made by a psychiatrist. Secondary deviance, in contrast, refers to the effect the label subsequently has on both the person being labelled and other people around them. Being called 'demented' or 'confused' is likely to lead to others talking down and infantilising and this, in turn, can lead to the person with the label responding in ways that reinforce the original application of the label.

Goffman (1968) has shown how secondary deviance has negative effects. Certain disease labels have stigmatising effects. Thus stigma

refers to a relationship of devaluation in which one individual is disqualified from full social acceptance. Stigma is a social attribute which is discrediting for an individual or group. People with dementia are likely to be stigmatised because of their 'out of the ordinary' or problematic behaviour (Dingwall 1976). The bizarre behaviours characteristic of people with the disease clearly challenge social norms regarding appropriate conduct. There is an absence of research-based evidence of the presence of stigma in dementia (Macrae 1999), but this may reflect the nature of the disease in which people with dementia may not be aware of negative responses to their behaviour. Biographical accounts, however, written by people who were in the early stages of dementia, indicate that some individuals experienced embarrassment and shame (McGown 1993).

Although symbolic interactionists offer other explanations of social phenomena, they often remain uncritical, emphasising the range of explanations. Phenomenologists have provided a more critical approach by focusing on the meaning that the condition has for people with dementia:

A phenomenological perspective requires that our understanding of dementing illness be empirically grounded in the 'lived experience of those who have the condition' (Lyman 1998: 49).

The meaning and quality of life is only meaningful through the subjective definitions of individuals. This perspective is problematic within the biomedical or psychological model of dementia because of the expectation of a profound loss of self. The phenomenological perspective challenges the deterministic biomedical model of disease progression in which dementia is characterised as an inevitable decline in cognitive function and the development of associated behaviour problems. Accepting that dementia can be characterised by functional impairment, the phenomenological perspective argues that many of the problems of dementia are socio-environmental and not biomedical. It focuses on the experience of illness rather than disease progression. In contrast to the deterministic perspective of the biomedical model which attributes an individual's functioning and behaviour problems to the neuropathology of dementia, phenomenology offers a perspective which modifies the social and environmental conditions affecting the illness experience. Living with dementia involves the active creation and re-creation of meaning and identity, and the negotiation of empowerment, as part of the daily work of living with the condition. Studies of the meaning of dementia from the perspective of the person with dementia and their carers have highlighted its complexity and

variability (Gubrium and Lynott 1985; Gubrium 1986, 1987; Askham 1995).

Postmodernism has examined the loss of self in dementia through the social constructionist view of the nature of self (Sabat and Harré 1992). From this perspective two kinds of 'self' have been identified. The first is the self of personal identity in which one's sense of personal agency supports continuity of purpose and meaning in life. The second sense of self is the one which persists 'behind' what Goffman called 'personae'; this is the self which is publicly displayed in everyday interaction (Goffman 1971). In their analysis of the construction and deconstruction of self in dementia, Sabat and Harré refer to the first as 'self' and the second as 'selves'. Linguistically we display the 'self' through indexical expressions such as 'I' and 'you'. There is a singularity of meaning which can only be interpreted when one has the knowledge of the person who uses them and in the context of their use. In contrast, 'selves' are the variety of different ways of behaving in the social world and will be dependent on the social context.

Social constructionist theory has provided new insights into our understanding of dementia. 'Self' remains intact during the course of dementia despite the loss of cognitive and motor functions and, perhaps, the loss of the indexical creation of self (Sabat and Harré 1992). The threatened loss of self does not appear to be linked to the 'progress' of the disease but rather to the related behaviour of significant others. They interpret the loss of the indexical creation of self as a loss of self, and interpret the presentation of 'selves' as indicative of loss of self. Thereby they create their own reality and language to describe the presentation of self by the person with dementia. In practice the resultant loss of 'selves' leads to loss of autonomy and a loss of personhood.

Methods used in the study of dementia

Health services research remains primarily a social science and is therefore a social and political act. To do social science we watch, we listen, we ask questions and we interpret our knowledge in the light of existing knowledge, beliefs and opinions. The challenge for health services research is to develop appropriate methods for investigating the effectiveness and efficiency of interventions for dementia from the perspectives of the individual with dementia, their informal and formal caregivers, the public sector and society. A range of health services research methods have been used in studies of people with dementia

TABLE 2. *Methods used in studies of dementia*

Quantitative designs and methods
Randomised controlled trials
Case-control studies
Surveys
Qualitative designs and methods
Participant observation
Ethnographies using:
<i>interviews</i>
<i>documents</i>
<i>direct observation</i>
Action research
Dementia care mapping

(Table 2). Our key concern in this paper is the perspective of the person with dementia.

If we view dementia as a social phenomenon rather than simply as a medical category, we need to ensure that the methods we use will de-medicalise dementia. Our approach in understanding the meaning of dementia, and in describing the experience and impact of dementia and of health and social care interventions, should take the perspectives of the person with dementia and their informal caregivers. In short it should ensure that the integrity of an individual's personhood is maintained.

Quantitative or qualitative?

The hegemony of positivism in health services research in which quantitative research is treated as a technical matter, relegates qualitative research to the status of junior partner. But, whereas qualitative research is linked to philosophical and theoretical assumptions, investigations using quantitative methods are often atheoretical. A key contrast here is the 'positivist' notion that the world has existence independent of our perception. Other social science paradigms suggest there are multiple realities since our external world consists merely of representations, and is a creation of the mind. The different assumptions and epistemological origins of quantitative and qualitative research methods imply that methodological pluralism is probably inappropriate.

In comparing qualitative and quantitative methods a distinction is often made between the use of deduction and induction in the analysis of data and in the development of new theory. Deductive method underpins positivism and the statistical designs of quantitative analysis

(Popper 1961). But deductive method can only be applied to studies which are hypothesis testing. Much quantitative research is descriptive and seeks empirical generalisation and is therefore inductive. Qualitative research is primarily inductive, being descriptive and steeped in the traditions of grounded theory (Glaser and Strauss 1967) and analytical induction (Robinson 1951). The process, however, frequently involves hypotheses testing which in turn involves deductive reasoning. Therefore both inductive and deductive approaches are appropriate for quantitative and qualitative research.

Another often cited contrast between quantitative and qualitative research is the artificiality of experimental and other quantitative methods and the naturalism of qualitative research. 'Central to naturalism is the desire to represent the world as it is, in all its complexity and changeability, and to avoid imposing artificial structures' (Hammersley 1989: 157). Yet all researchers are inevitably part of the social world in which they research and act. So qualitative researchers are as likely to influence the nature of the research setting as are quantitative researchers in artificial experiments. The artificial/natural debate is therefore more about the way that researchers seek to *structure* the research situation than its inherent characteristics (Murphy *et al.* 1998).

The structure of qualitative research

The use of qualitative methods in health services research has a number of distinctive features. First, there is a commitment to viewing events, actions, beliefs *et cetera*, from the perspective of those being studied. This commitment is essential in the study of people with dementia if we really take personhood seriously. The commitment to understanding participants' perspectives implies investigating the experience, meanings, intentions and behaviour of people with dementia on their own terms. This inevitably means using fieldwork methods which get the investigator close to the subject of study. In practice such a commitment is impossible to meet. This is not because people with dementia are different from other members of society but because members' accounts cannot be independent of the interpretation that investigators may place on those accounts.

...inevitably fieldworkers comprehend, interpret, and code in memory ongoing social activities in ways that depend upon their presupposition, general cultural knowledge, prior experience in and particular knowledge of the setting. (Emerson 1981: 358).

With dementia this is compounded by the investigator lacking any real

experience of having dementia. Those of us who have experience of living with or caring for a person with dementia will have some important complementary experiences, but these may lead to misguided interpretations of the real experience for the person with dementia.

With these qualifications in mind, the focus of qualitative research, more than that of quantitative research, can therefore be on understanding members' meanings and practice. The research tradition of focusing on meaning in dementia rather than on both meaning and practice, is dangerous. Although members in general and people with dementia in particular may have the relevant knowledge and experience, they may not have the ability to articulate their perceptions of it to the investigator. The presence of both public and private accounts (Cornwell 1984) within participants' accounts, makes it difficult for the investigator to interpret the accounts they are given. Even within qualitative research, the private account is securely hidden until the investigator is able to establish empathy and close relationships with participants, processes which are not always feasible. The public account, the account that the participant assumes the investigator wants to hear or which is constructed with the public accounts of others, dominates (Corner 1999).

Meaning is also difficult to reproduce, given the reflexive nature of participant-investigator relationships. Of course this is not a problem specific to the study of dementia. A radical critique of the method has a long tradition in sociology and can be traced back to issues discussed by Cicourel (1964) and Dingwall (1997).

A second common feature of qualitative research is the emphasis upon the description of the setting being investigated. In line with the inductive approach to theory development in qualitative research, description is used in the first stage of theory development. Description is also essential to providing first-hand experience of the context of interest which might otherwise be inaccessible to the investigator who has no direct experience of dementia or dementia care. Qualitative research also has a commitment to providing a full description for the reader that is distinguished from everyday routine description by its detail, albeit interpreted by the investigator. In providing descriptions, it is therefore essential that the investigator provides the value and factual assumptions which underpin such descriptions and justify them theoretically. Description in qualitative research plays an important role in challenging or undermining taken-for-granted assumptions about the nature of the setting or of the participants under study.

In contrast to quantitative approaches, particularly experimental

designs such as the randomised controlled trial, which seek to control social action in order to isolate cause and effect, qualitative methods emphasise context and the complexity of social reality. Thus, rather than isolate the complex social world, it is placed in the centre of the research stage. This perspective is also important in many situations where quantitative approaches are used. For example, in much dementia research, the focus is on the 'measurement' of attributes such as cognitive ability or quality of life. Understanding whether the investigator is measuring what is intended, requires a detailed understanding of what influences scale properties. Qualitative methods enable the investigator to explore with participants the complex interplay between the various factors. In evaluation research, qualitative methods are extremely useful in understanding what is going on 'inside the black box'.

Qualitative research also places an emphasis on process. Without an analysis of process, investigators cannot claim to understand any causal link between interventions and outcomes in experimental designs or, more generally, between A and B in causal modelling. Focusing on process is particularly useful for identifying why certain generalisations do not always hold. In dementia research, where the eventual outcome is death, an exploration of intermediate outcomes and processes is essential for estimating the effectiveness of interventions.

A distinctive feature of qualitative methods is the flexibility of research designs, particularly where ethnographic methods using a range of techniques are involved. The reluctance to impose a priori theoretical frameworks at the outset (Bryman 1988) implies an insistence that the social world must be discovered through observation. Relying on what people say because of public and private accounts is likely to result in distortion. Thus, there is a need for emergent research designs to be theoretically driven.

The contribution of qualitative methods to health services research needs to be considered within the context of research questions and study objectives. As we saw above, measuring outcomes which take the perspective of people with dementia challenges positivism and quantitative methods. To address the criticisms of the traditional approach to the measurement of quality of life, for example, implies the use of qualitative methods underpinned by substantive theory. But how might qualitative methods be used to 'measure' quality of life? In qualitative research the notion of measurement in this context is problematic (Cicourel 1964). The description and explanation of differences in observed and perceived quality of life among people with dementia, may provide an answer for the broad study question, but

specific questions and objectives would need to accommodate a shift in perspective.

The use of qualitative methods to investigate quality of life in people with dementia is methodologically and practically challenging. From ongoing work we can illustrate the value of taking the perspective of the person with dementia and of using qualitative methods to capture that perspective. Of course, as we have already indicated, we will never know whether our accounts are the true accounts of study participants or a different reality engineered by the interaction between theory and qualitative method. What we can say is that the research outcome is different. The following description of Dennis (a person with dementia) and Margaret (his wife and carer) illustrates how qualitative methods might be used to investigate the quality of life of people with dementia.

Margaret and Dennis

To understand the quality of Dennis's (and Margaret's) life required fieldwork which was labour intensive. The qualitative method used could be characterised as a form of participant observation rather than simply a series of qualitative or unstructured interviews. It was participant observation because of the extensive use of 'informal' observation over time used to construct the following description. Only by becoming a 'friend' of the couple was the observer able to elicit accounts which triggered interpretations which could then be tested at subsequent visits (observation plus interviews). In addition a life-history perspective was used with Margaret and Dennis, to provide a context for their ongoing discussions about their experiences of dementia, and about adjustment and the coping strategies they used in the course of the disease.

Margaret and Dennis have been married for 35 years. They live in a modern terrace house, which has been adapted to suit Margaret's needs. She has severe arthritis and oedema in her legs and, while she can walk around the house with two sticks, she finds it difficult to get up from a chair alone and has had a stair lift fitted. With the use of an electric wheelchair she remains independent.

Dennis is an athlete. His physical build is lean and slight and it is not hard, on meeting him, to imagine him pounding the pavements pursuing his passion for long-distance running. For over 25 years he has been an active member of a local running club, training with fellow members for marathons, completing daily training runs and exercising in the gym. Through the running club, he ran competitively throughout his long career, completing over 25 half marathons and, the crowning

achievement, completing a local marathon in three hours, 10 minutes. The running club also constituted a major part of his social life; he and fellow members met once a week in a local pub and he had developed many close friendships with other club-members. Running was clearly important to his quality of life and to his sense of identity. Keeping physically fit was also hugely important to him. He eloquently described the sense of freedom he had always felt when running, how he found running relaxing and how he cleared his mind, running on 'auto-pilot'. The sense of achievement he felt when completing a run was 'fantastic':

Your body feels good all the time, that's what it feels like, it drives you on because you are wanting to do that all the time and get faster. (Interview 2; page 19, line 18)

This passion and enthusiasm only came to light following a chance remark by his wife, when discussing 'days gone by'. When questioned about what is important to their quality of life, neither had raised the topic. It was only after several interviews that the topic came to light.

Dennis had been experiencing memory problems for six years when he was diagnosed with 'probable Alzheimer's'. Almost immediately following this diagnosis Dennis withdrew from running. Friends from the local club no longer contacted him to join them. This had been particularly hurtful to Dennis and he had felt unable to contact his friends, and his closest friend in particular, for an explanation as to why the contact had ceased. Margaret explained:

... a friend of his, a very good friend actually, they've been running for years together, came out and saw him last year and said 'Right, Dennis, I'm still running ... I'll come and pick you up and I'll take you and I'll bring you back, give us a ring if you want to go'. So, I says 'Do you want to go?' 'Yes'. So I rang and told him he wanted to go and he never rang back and that really, really upset him. I don't think he ever got over that yet. (Interview 1 with Margaret; page 9, line 1)

Dennis's wife, Margaret, described the effect that this incident had had on Dennis:

I think he's frightened of getting let down again, you know ... he's frightened to trust again. (Interview 1; page 9, line 27)

Margaret felt Dennis could no longer go out running, focusing on the perceived risks involved and the potential consequences. She expressed her fear of him being hurt, getting lost and unable to find his way home. Dennis no longer goes out running. He said that he wished he could still run, and felt that he still could. Physically he remains fit and lean, still with the body of an athlete but, possibly following the diagnosis of dementia, restrictions have been placed by others on his choices.

We present this description of this case study to illustrate how qualitative methods can unlock accounts and provide the perspective of the person with dementia.

Action research

The methods of action research provide a different approach to the study of dementia. Action research has a shorter history in social science than either quantitative or qualitative methods, emerging as a distinctive style of research in the 1940s (Lewin 1947). The approach is different from traditional approaches because of the way that research is done *with* people rather than *on* them. Contemporary action research will use a range of methods but more often uses qualitative than quantitative methods, sharing many of the epistemological assumptions of qualitative researchers, particularly the importance of taking the perspective of the other. The contribution of action research to knowledge, however, is different from other styles of research. Whereas traditional quantitative and qualitative approaches attempt to provide description, explanation and prediction, action research is a process which facilitates social change. It can be distinguished from other styles of research by the researcher and participant sharing the goal of generating social change. It has been widely used as a tool for changing professional practice (Hart and Bond 1995).

Action research incorporates three key elements: participation, democratic principles, and commitment to change (Meyer 2000). Participation in action research by ‘consumers’ (Cochrane Collaboration 2000) is more than involving consumers in defining research priorities, assisting in the recruitment of participants for studies, collecting data or writing up and disseminating results (Hanley *et al.* 2000). Participation in this way is likely in action research but it is not only the shared commitment to change which distinguishes the approach but also the democratic principles essential for the resolution of any conflicts which emerge during the research process. The democratic principles of action research imply that researchers and participants are treated as equals in the enterprise. The researcher is the facilitator of change, consulting with participants at all stages of the research process and, in particular, feeding back findings and interpretations of findings to participants on a regular basis. This collaborative style leads naturally to the research process adopting a spiralling sequence of planning, acting, observing, reflecting and replanning.

In dementia research the principles of action research are clearly

encapsulated in the use of Dementia Care Mapping to change the quality of institutional environments for people with dementia (Kitwood and Bredin 1992*a*; Kitwood 1997*b*). Dementia Care Mapping is grounded in the social psychological theory underpinning the concept of personhood (Kitwood and Bredin 1992*b*; Kitwood 1997*a*) and attempts to take the perspective of the person with dementia through the use of skilled observation and empathy. It provides a basis for understanding the process of care that organisations provide. A facilitator, initially a researcher but increasingly a Dementia Care Mapping Project Leader (Williams and Rees 1997), in partnership with staff, brings about change in organisational culture through the 'developmental loop', leading to improvements in the care of people with dementia. The success of Dementia Care Mapping is evident in the fact that the manual is now in its seventh edition. However this success has led to inflated claims for the method, and to it being used for purposes not originally conceived by the authors, namely as a measure of quality of life as an outcome for clinical interventions.

Studying dementia and dementia care

Are there unique methodological challenges for health services research in the study of dementia and dementia care? We have argued that the methods used in health service research, predominantly based in social science, are unable to meet the rigid criteria of the biomedical model and of positivism. This is due to the complex and diverse nature of social experience. Early critics of positive methods proposed the alternative qualitative approach to method, as a way of overcoming the limitations of experimental and survey methods. Because of the different epistemological assumptions of these contrasting approaches, it was argued that it was not possible for quantitative and qualitative methods to be combined within studies. Yet much of the debate has been ideological and not grounded in epistemological or theoretical concerns. Increasingly within health services research, quantitative and qualitative methods have been combined to investigate relevant questions. Where this has been successful, investigators have recognised the complementary nature of these approaches. In studies of older people, but particularly where older people have cognitive impairments, the use of qualitative interviews has been essential for collecting complex data for understanding participants' meaning and practice within the context of experimental designs (Bond *et al.* 1989). In such

studies the use of qualitative methods has often increased the contribution of theory to the overall investigation. In recognising the complementary nature of qualitative and quantitative methods it is essential to acknowledge that all social science research is challenged by the nature of reflexivity, and is subject to social construction by individual investigators. Hence, the central role of theory in mediating individual interpretations and the need for systematic documentation of all data and of the investigators' values and interpretations of that data.

The phenomenological perspective argues the need to study dementia through the lived experience of people with dementia. Although it is 'politically correct' to listen to the voice of older people, there exist inherent dangers in focusing on members' accounts, irrespective of their social characteristics, as Dingwall (1997) has clearly described. Radical critiques of interviews indicate that rather than giving an accurate description of external reality they are grounded in the context in which they are produced. But it may be that glimpses of the reality of members' accounts can be gained through the way participants present their accounts; for example, the choice of facts selected and the way facts are selected. In everyday conversations we learn to recognise that reported events are a mix of reality and storytelling, and therefore only act as representations of reality. It may be that conversations with people with dementia are more a reflection of their internal reality than the representations of others. Caution is advised, however, whether or not participants are people with dementia. Focusing on members' meanings has substantial shortcomings and investigators may get closer to reality by focusing on participants' practices rather than their meanings.

Qualitative research methods are well suited to the study of dementia. The particular strengths of qualitative research include the ability to examine socially meaningful behaviour, albeit deviant behaviour, holistically, in context and with due attention to the dynamic aspects of social events and interactions. The emphasis on flexibility of design makes it well suited to hypothesis generation and discovery, while its reluctance to impose theory at the outset has significant potential for undermining the taken-for-granted assumptions of current biomedical-oriented knowledge. Although qualitative methods can play a significant role in studying dementia and dementia care, this should not be to the exclusion of quantitative methods since there will always be a need to describe quantitatively characteristics of social settings.

So, are there unique methodological challenges for health services

research in the study of dementia and dementia care? No, rather the complex nature of dementia and dementia care highlight the challenges we have in the investigation of any complex social phenomenon. The study of dementia makes obvious the strengths and weaknesses of our social science toolkit of methods and techniques, and increases our understanding of the taken-for-granted assumptions of social science research. Rather than the study of dementia and dementia care being difficult to study, it is the weakness of dominant methodological approaches and lack of theoretical rigour in health services research which militates against successful understanding and explanation of the phenomenon.

NOTE

- 1 The 95 per cent confidence interval for this estimate of the percentage of people aged 65 or over who have dementia is 5.9 per cent to 7.3 per cent (MRC CFAS 1998).

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Accepted 17 November 2000

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