

Thesis
3712

'They come here to tangle':

**An ethnographic study of relationships of
people with dementia**

Gillian Margaret McColgan

**Thesis submitted for the degree of
Doctor of Philosophy**

**Department of Applied Social Science,
University of Stirling
2001**

05/02

Abstract

This is a sociological ethnography of nine people with dementia living in a private nursing home in central Scotland. It seeks to find an alternative way to view people in this situation, in a field that has been dominated by the medical model. By placing the people before the disease of dementia, they can be studied within the same framework as any people. For this study this framework is everyday life sociology with a focus on symbolic interactionism, ethnomethodology and dramaturgy. Additionally, by gaining the subjective perspective, we can get close to understanding meaning for these people. The ethnographic methods I use consist of participant observation and interviews. For analysis I employ NUDIST to structure the data and the thesis. The setting, Lavender Wing of Deer View Grange Nursing Home, provides context for the study. This is a culture of surveillance and routines, which can be restrictive, infantilizing and disabling for residents. Despite this culture research findings are of socially active participants. By examining relationships through an interactional framework three thematic areas developed concerned with emotions, interactions and classification. These thematic spheres demonstrate the emotional self, the interactional self and the generalized self of research informants. The emotional is concerned with the most inner and intimate self, often engaging in backstage intimacies and in thought. Significant others share with the interactional self, in frontstage performances, which are more ritualistic. The generalized self interacts with the generalized other, most often consisting of everyone in Lavender Wing and is concerned with classification and boundary definition. Within these

spheres the described relationships are fluid and change according to the situation, and how participating actors define it. To engage in intimacies, rituals and form, and to shift between them requires social competence and active participation. People in this study demonstrate these. Despite restrictions they offer resistance to the environment and to dementia. They often make profound and metaphorical statements, to which this ethnography gives voice.

Keywords

Everyday life; interaction; nursing home culture; people with dementia; resistance; self and others; social competence; surveillance.

Acknowledgements

There are many people who have contributed to this study and to my understanding of being a person who has dementia. They fall broadly into three communities: informants, academic advisors and personal supporters.

Firstly, there is the group of people in Deer View Grange Nursing Home who informed the research: the residents of Lavender Wing, without whom this study could not have taken place. Although they did not directly inform the research, I must also acknowledge those who support the residents – staff and management of the Grange, and families of and visitors to residents.

Secondly, there is a community within the Department of Applied Social Science and also the Centre for Social Research on Dementia within this Department at the University of Stirling who have contributed in their support, advice and guidance throughout the study. Staff and PhD students, past and present, have given both frontstage and backstage contributions of this sort. Most notable in this have been my supervisors Alison Bowes and Jim Valentine, both of whom provided constructive comments and continual motivation for this work. Others are too numerous to name, so I apologise to anyone that I should have mentioned. Sharon Wright, Rhoda MacRae and Jacqueline Davidson have all shared an office with me at some stage in the research and helped me work through parts

of the thesis. Beth Crossan gave me the opportunity to work with her on the issue of consent, work that informed this study. Paul Duckett helped me in the early stages of the study, questioning my ethics as researcher, as did Charlie Murphy. Murna Downs provided an alternative perspective to my sociological one and an invaluable introduction to dementia studies. In support of the finished product outside the department are those who read and commented on my written work, Penny Furniss and Patricia Bascom.

The third community who have also contributed significantly and in a very intimate and backstage domain are personal contacts who were there when I needed them and kept their distance when I needed 'space' to work. Of these, I must especially acknowledge my partner, John Gibbs, for whom life has changed during the course of this study and may never be the same again. Without him, I might not have eaten cooked meals, or kept a sense of reality.

To all these contributors I extend my thanks.

Contents

Part A: Theoretical background

Chapter 1: Introduction 1

Chapter 2: Whose dementia is it?

Issues of power, control, rules and resistance .. 9

Conventional accounts on dementia

Age: stereotypes and images

Medical model of dementia

Learning from disability studies

Social research on dementia

Relationships

Social support

Power, control and surveillance

Nursing home culture

Rules and resistance

Conclusion

Chapter 3: Everyday life in the social world 54

Shared symbols in relationships

Form and ritual

Strategic interaction

Dramaturgy

Differentials in power and labelling

Definition of self through others

Narrating selves

Boundary definition

Sociology of emotions

Conclusion

Chapter 4: Gaining the subjective perspective:

Methodological considerations 98

Access, ethics and informed consent

Consent

Fieldwork

Ethnography

Participant observation

Interviews

Fieldwork in perspective

Recording data

Conclusion

Part B: Analysis **126**

Chapter 5: Analytical beginnings:

Introducing the stage and players **130**

Analysis

The setting

Research participants

Conventions used in writing

Conclusion

Chapter 6: Social benefits and constraints of

living in a nursing home **150**

A day in Deer View Grange

Benefits of living in a nursing home

Constraints of living in a nursing home

Conclusion

Chapter 7: Emotions and dementia **179**

Residents' emotions

Dementia and emotions

Emotional support

Conclusion

Chapter 8: Interaction	218
People					
Content					
Form					
Conclusion					
Chapter 9: Boundaries	256
Physical boundaries					
Boundaries of self and other					
Situational domains					
Rules and resistance					
Liminality of people with dementia					
Conclusion					
Chapter 10: Conclusion	305
Bibliography	320

Appendices 349

Appendix A: Research plan submitted to Deer View

Grange Nursing Home to gain access

Appendix B: Plan of Lavender Wing

Appendix C: Plan of lounge and dining room of

Lavender Wing

Appendix D: Coding of nodes for structuring data

in NUDIST

Chapter 1: Introduction

This ethnography is about people. That is something I want to state at the outset. Specifically, it is about the people most directly affected by dementia, those who have it. They are the focus of this study.

This account seeks to explore from a position of minimum pre-conception. The study from which it grew was in enthusiastic response to a new Centre for Social Research on Dementia, which was established at the University of Stirling towards the end of 1997. The Centre's aim is to redress the balance in knowledge about dementia, which has failed to take account of social factors. Organized into themes, projects were already under way to meet the Centre's aim and were concerned with evaluation and early detection of dementia. The theme that was not being covered was concerned with 'The social meaning of dementia'.

I joined the Centre as a research student in 1998, with a background in sociology, an interest in relationships and little knowledge of dementia. As I had not come across a wide sociological literature concerning dementia, there appeared to be scope to develop a study in a relatively new area of research making use of my existing interests. Additionally, it seemed that branching into this new area of seeking the social meaning of dementia also required development of appropriate methodologies. This would also contribute to a further theme of the Centre for Social Research on

Dementia: 'methodological issues and developments in researching dementia'.

My interest in relationships provided an appropriate means to explore the social meaning of being a person who also has dementia. I wanted to gain a depth of understanding of this and wishing to explore the subjective view, I needed to go beyond third party accounts used by others, or engagement in role play and to learn at first hand from people who had dementia. My first aim, then, was to study the subjective perspective on dementia.

My aim determined that it should be a qualitative study because of the depth of information required, and this in part determined my choice of setting and my methodologies. After considering a number of options, I felt that what I was trying to learn required continuous study over a period of time. I did not want snapshot views of an instance, which would not allow me to get to know individuals. If I were to achieve understanding through relationships, this also needed to be set in context of individuality and difference, rather than treating all the people in the study as an homogeneous group.

A number of decisions about the research design were made simultaneously, as the method suggested the setting and the setting suggested ethnographic method. I also felt that study for my doctoral thesis might be my only opportunity to conduct ethnography, as funding for this type of research is often difficult to obtain. The appropriate setting for

the research became determined as one where a number of people with dementia live. Many such settings house older people, some of whom also have dementia. The setting I chose was a nursing home where all the residents have dementia.

My second research aim did not become established until after I had met my research informants and also read academic literature on dementia. There was a conflict in the information I was getting from these two sources. The literature spoke of decline and loss associated with dementia and these images provoked fear. It was indeed, a dismal picture to gain before starting fieldwork and I was very apprehensive about this. Perhaps because of the negativity of the literature, it was something of a surprise that residents in the study appeared as people. They talked to me, they looked like other older people and there did not seem to be reason to fear them. I wanted to be able to convey this impression to others, that people with dementia are still people and they should not be feared. I needed to show that they have characteristics of people and I now wanted to determine that these residents were active social participants.

These became my research aims: to explore the subjective perspective of dementia and to determine if research informants were active social participants. In the thesis, using ethnographic method I attempt to construct the subjective view of people who have dementia. I use their words when possible, and I express what they have told me and what I have seen. I interpret within the theoretical basis of the study and in the context of the

setting. By studying in a nursing home I have sought to find what everyday life may be like: to understand the social world for someone who has dementia.

The words of one research participant provide the title for the thesis: 'They come here to tangle'. This expressed what life in a nursing home was like for her on some days and it is said in her voice. The context in which this was said provides the meaning of the phrase. She was talking about people coming in and out of the lounge in which we were sitting, as often occurred. She was using a substitute word, which was also a frequent occurrence, which had a similar meaning to 'mix' or 'socialise'. The phrase summed up, more eloquently than I could, what the thesis is about, the relationships of people with dementia living in a private nursing home.

That this title came from a research participant highlights a key element of ethnography and specifically of this study. This element is voice, which both expresses subjectivity and shows social meaning. I do not seek to liberate or empower the people involved in the research. I am attempting to project an image that may help to produce alternative views to those that focus on disease rather than people. Two ways in which this may occur are by facilitation of voice so that people with dementia can express themselves and their preferences, and by finding ways in which others can hear what they are saying. Through ethnographic writing, residents' words and expressions can be given permanence. It is my hope that this will

advance our understanding of the social meaning of dementia and that we will learn to hear what people with dementia say.

Having provided some rationale for my approach and the subject area I now outline the rest of the thesis.

Arrangement of the thesis

With research aims established above, in Chapter 2 I ask 'Whose dementia is it?' This is focused theory considering different perspectives and attitudes to dementia. By examination of what perspectives have been used to date and the resulting attitudes that these have produced, then thinking in alternative ways, we can see how perspective frames impressions. This is also a way of examining how a perspective for social research on dementia may look. Relationships and social support are discussed. In this study, there are other considerations that also have to be examined relating to the culture in which residents live. Power, control and surveillance, and rules and resistance all relate directly to the environment, have relevance to residents and are a part of everyday life for them.

Having now positioned the person before dementia, Chapter 3 moves into the social world of everyday life, exploring the theoretical background for the study. This study is about people who have dementia, but because primacy is given to the fact that they are people rather than that they have

dementia, then an appropriate theoretical framework is one appropriate for any group of people. It is a study of everyday life, and a number of theories provide this framework. Aspects of symbolism, interaction, strategy and dramaturgy are considered together with emotions, to explain how shared meanings are conveyed and understood. Ways of defining are also important, including labelling, self-perception and boundaries. These constitute the basis of the background theory for the ethnography.

As limited work has been completed to date that takes account of the subjective perspective on dementia, appropriate methodologies need to be found. Chapter 4 is concerned with methodology. The way that the research is conducted is important for the facilitation of voice. In addition to considering how to gather the data, other matters relating to access, ethics and consent are discussed. These are relevant to all research but the sensitivity of them is highlighted when research participants are also considered to be vulnerable, as in this case. There may therefore be implications in these methodological considerations which go beyond the scope of this study.

The above chapters form the basis of the background to the study, which constitute Part A of the thesis. Part B is concerned with ethnographic description. Conventions used in writing this are outlined in Chapter 5. This is the first analytical chapter and relates to introduction of the setting and research participants. Analytical themes emerged and developed during fieldwork on the basis of the two research aims of gaining the

subjective perspective, and exploring active participation amongst residents. The significance of the nursing home effect on social activity became apparent and is the topic of Chapter 6. Drawn from empirical evidence during the study this gives further context to it. Further empirical data led me to analytically develop three substantive themes which all related to and emanated from subjectivity.

The first substantive theme area is shown in the analytical chapter relating to 'Emotions and dementia' in Chapter 7. The first aspect of the active social participant is displayed as emotional. This concerns the most inner self, relating in backstage performance. A range of emotions is considered as arising in research. Some emotions appeared connected to or accompanying aspects of dementia and are discussed in relation to confusion, wandering and awareness of dementia.

The second aspect of the active social self is revealed in interactions, the subject of Chapter 8. More formality and frontstage performance is often associated with these. Frequently involving ritual, they present an opportunity to examine social competence and participation.

Boundaries and boundary definition is the theme of the third analytical chapter relating to active social participants, Chapter 9. Here consideration is given to physical boundaries, self and other, and the situational domains arising from frontstage, backstage, inside and out. Restrictions arising out of the nursing home culture and from dementia can place residents in a

confinement situation, but it is one they can be seen to resist in various ways. Finally, the boundary situation of liminality is given consideration in relation to older people who have dementia.

These analytical chapters of Part B provide evidence to satisfy the research aims of gaining the subjective perspective of dementia and examining active social participation of research informants. Voice is given through ethnography, and social competence and active participation are shown.

Having outlined the arrangement of the thesis, more detailed scene setting can now begin. This will start with the examination of theory relating to the person with dementia.

Chapter 2: Whose dementia is it? Power, control, rules and resistance

The examination of the social world of research participants is set in context by investigation of perspectives on dementia, and the differentials in power which may cause vulnerable people to be controlled and subjected to rules. In the past, dementia research has been undertaken predominantly from the medical point of view, which places disease before the person, and is phrased in terms of loss and decline. This perspective sees people who have dementia as passive recipients of care. Alternative models could dispel stereotypical images conjured by negative views of ageing and dementia and show these people as active, and able to offer resistance. When the subjective experience of ageing has been studied, for instance, people have expressed the view that they feel veiled in a 'mask of ageing' rather than feeling, as stereotypical images of ageing suggest, old and useless. To understand what it is like to have dementia from the subjective experience will similarly reveal emotions which have been masked in perspectives described from the point of view of others.

Disability studies will be explored to provide lessons in how we can progress towards a model for social research on dementia. Relationships and social support will be discussed to aid this progression and our perceptions of people who have dementia.

Furthermore, the social world of people who have dementia and are participants in the study, needs to be set in the context of the environment in which they live. The use of surveillance and control within nursing homes demonstrates inequalities of power in relationships, which maintain residents in subservient and vulnerable positions. Rules are an intrinsic part of this environment. However, I wish to show research participants as active and able to make effective escape attempts as a means of resistance to everyday life.

This chapter is key in setting the scene and raising concerns for the study. It introduces issues which will develop throughout the ethnography, starting from conventional accounts of dementia.

Conventional accounts of dementia

If we are to gain a sense of what dementia means to the everyday lives of people who have it, and those who care for them, an exploration of fiction and personal biographical accounts may be useful. Hepworth (2000) has explored *Stories of Ageing* as a means of understanding the ageing experience. Amongst many of the fictional accounts he examines are those of dementia. As he points out:

Because of the variety of perspectives which are possible in imaginative fiction the reader may be guided towards a deeper understanding of the person with dementia. Hepworth, 2000: 16.

The subjective view is difficult to gain and understand, and fictional imagination thus allows the construction of what it may be like to experience dementia. The use of various perspectives adds to the image

and also gives context to the experience. Individuals may be shown 'in the rich context of their family and social life', and often from the perspectives of different actors (Manthorpe, 1996: 27). Relationships feature strongly in fiction and demonstrate the intimacies and subjectivity of those involved.

Two women's voices narrate in *Have the Men Had Enough?* (Forster, 1990). Their relationships to 'Grandma' who has dementia, are daughter-in-law and granddaughter. The story is one of love, obligation and the turmoil created by dementia for all concerned. The characterisations show the elderly lady with dementia and her principal carer as vulnerable and not coping, almost inevitably leading to the need for residential care. Fears and guilt feature strongly. Grandma clearly has a voice and is given character by the author, yet when decisions about her life are made her voice is silenced.

A son's story is told in *Scar tissue* (Ignatieff, 1994). This also is a study of relationships and the impact that dementia can have on them. His mother has dementia and his parents grow closer through this: dependency creates a bond. Conversely, as he attempts to help his parents, his own marriage partner and young family become more distant. The story shows decline, loss, and a disparity of perspectives between a son's concern for his mother's well-being and the neurologist who reduces her to a case-study.

Both of these novels are well enough researched to allow the reader to identify with the experiences that dementia presents. Some additional insight into dementia can also be gained from accounts written by people in the early stages of the condition (for example Davis, 1984; McGowin, 1993; Rose, 1996). The titles of each of these books suggest journeys into dementia, being engulfed and lost, and wishing to go home. Davis describes memory difficulties, panic and confused emotions:

I feel both good and bad emotions at the wrong times ... there is little or nothing that I am capable of doing to change my emotional feelings. I simply have to live through them and continually discount the effect they have on my judgement. Davis, 1984: 109.

This perceived effect of emotions upon rationality is interesting, and a common characterisation of people with dementia. McGowin went through many emotions after she was diagnosed with Alzheimer's disease at the age of 45 years. Many of these were concerned with the relationships she had with others and how these changed as a result of her diagnosis. She also felt a sense of loss, consistent with suggestions in academic literature that will be seen later:

... there are many days when I am painfully aware that less of me exists than the day before. McGowin, 1993: 116.

The sense of loss is also echoed in two biographical accounts by daughters of people with dementia; *Losing the Dead* (Appignanesi, 1999) and *Remind Me Who I Am, Again* (Grant, 1998). These accounts have been described as 'confessional' and presenting 'a whole series of perceptions' (Manthorpe, 2000: 35). I found that they were concerned with the relationships between mothers and daughters. As their mothers' memories fade, they try to (re) construct their pasts, ever conscious that part of their

own biographies is tied to those of their mothers. This may be a vital clue to the association of loss of self for people with dementia, that the practice of gaining second-hand accounts of dementia will reflect the sense of loss that others feel.

Both also illustrate the complexities of mother and child relationships changed by children reaching adulthood and appreciating that their parents had pasts and features not seen by the children. Characterisations of their mothers show repetitive behaviour and questioning, as things are constantly forgotten.

As Rose struggled with her memory, her daughter struggled to come to terms with the dementia diagnosis she had been given, in the knowledge that their relationship had been less than perfect. Like many family members, Grant sought information about her mother's illness, in order to cope with it. She found that in doing so there was a sense in which she had learnt more about dementia than about her mother. She asks 'Am I talking to a person or a set of symptoms?' (Grant, 1998: 265).

This sense of the person being taken over by the medical disease may have been due to the absence of a close relationship and could have engulfed a relationship that was close. There is little evidence of this, however, in Bayley's works (1998; 1999). He cared for his wife, Iris Murdoch the author, through her Alzheimer's disease. His two books are of their lives and relationships before and with dementia. In reading them

there is a sense of serenity and acceptance of the condition. In caring for his wife, Bayley felt their relationship strengthened and grew closer. In a diary entry just over a year before she died he writes:

Every day we are physically closer; and Iris's little 'mouse cry', as I think of it, signifying loneliness in the next room, the wish to be back beside me, seems less and less forlorn, more simple, more natural. She is not sailing into the dark: the voyage is over, and under the dark escort of Alzheimer's she has arrived somewhere. So have I.
Bayley, 1998: 183.

The metaphorical journey features yet again, and the escort is 'dark'. In the above quotation, Bayley also illustrates how intertwined the lives of the person with dementia and carer become.

Equally interesting as these very personal views of the experience of dementia are those more widely held, popular characterisations demonstrated in the reports and obituaries following Murdoch's death. An analysis of these showed dementia as the tragedy of the loss of mental capacity highlighted for someone known for their intellect, and the projection of images on to Iris Murdoch (such as goodness) whilst she remains silent.

Some of the accounts portray the dementia in essentialist terms, suggesting that Iris was demented rather than that she had dementia.
McColgan *et al*, 2000: 107.

This highlights the pervasive image of the person being lost to the disease.

Attitudes to dementia can be seen through examination of fiction, accounts by both carers and people with dementia, and also press representations. The picture is one of changing relationships, turmoil, vulnerability, loss,

decline and darkness. Carers try to hold on to or recapture the past, and feel guilt and fear if residential care is needed. Tragedy, a person lost to symptoms, reduced to being a case-study and journeying into dementia, are common themes.

The voice speaking loudest is not that of the person who has dementia, even when imagination and creativity permit, but of others touched by the experience. The personal accounts examined also appear to be as strongly influenced by popular representations and expectations of dementia as by experience. For instance, Davis voices fears of what is to come, rather than describing what the current experience is like.

Perhaps the exception to this black picture is shown in Bayley's touching memoirs. There is sadness and a black side associated with Iris's dementia, but the books indicate as much about the relationship between him and Iris Murdoch, as about her experience of dementia. This is of particular relevance to this study. By focusing upon Iris Murdoch, the person and upon her personal biography, she is not obscured by the dementia she experienced for a small portion of her life. This focus, it is hoped, may also be indicative of wider attitudinal changes regarding dementia; changes which will be influenced in many ways and social areas, one of which is social research.

Before discussing the position of social research on dementia to date, it would be useful to examine other influences upon attitudes. One such area

of interest relevant to this study, and also to older people who have dementia, is that of age or more specifically old age which is grouped broadly as gerontology.

Age: stereotypes and images

Age, and particularly old age, is also subject to characterisations and stereotyping 'constructed from a complex blend of discourse and sensory images' (Featherstone and Wernick, 1995: 5). When one group applies these stereotypical images to another it amounts to prejudice; when this is related to chronological age, it is ageism (Bytheway, 1997: 3). Whilst ageism is not exclusive to old age, this is the main way in which the term is used, and therefore has relevance to participants in this study.

Ageist assumptions about older people relate to moral panic and 'the dependency ratio', which is based upon economic activity and defined in terms of working ages. Thus people are defined as dependent when they are under 16 and over 64 years old (Bytheway, 1997: 52). However, children are seen as potential assets whilst older people are not. Blaikie points out that ageism arises both in social structures, as seen in policy, and in individual attitudes. These are legitimised by 'ideological supports' through 'biological reductionism', 'psychological explanations' and 'social justification', which deny rights, create dependency and suggest that older people 'want to disengage from society' (Blaikie, 1999: 17).

All of these are the ways that others perceive older people, and by virtue of the fact that a sense of self is often defined by reflections from others, or relationally to them, then negative stereotypes can impact on self-image. However, inner consciousness and outer bodily appearance often conflict in old age. This is described as the 'mask of age' (Hepworth, 1991).

When we catch a glimpse of ourselves in a mirror we are often surprised by the image we see, that we do not outwardly appear as we feel inside. This has been described as the 'mask of ageing' (Featherstone and Hepworth, 1988; 1990; Hepworth, 1991), a description of the disparity between the 'inner' self and 'outer' projection. Ageist assumptions are constructed on the basis of our physical appearance:

... it is the ageing mask which is pathological or deviant and the inner essential self which remains — even beneath or 'inside' Alzheimer's disease — as normal. Featherstone and Hepworth, 1988: 379.

Negative stereotyping of old age is related to culturally valued images of youth which are specific both temporally and culturally (Featherstone and Hepworth, 1990: 274). This specificity identifies them as socially constructed.

It has been shown that stereotyping of dementia and old age stigmatise older people with dementia, and that the views of old age differ from the subjective view. Both have a disabling effect, which becomes doubly so when older people experience dementia. This impacts on self-image, and causes tensions between the inner and outer person. These tensions may become more pronounced with a move into residential care in which life

becomes more public than private, and more involved in frontstage performances. In this sense the environment also has a disabling effect on the person who has dementia and finds themselves in unfamiliar surroundings. This is a point I will return to later.

Medical model of dementia

Much of dementia research to date has been from a medical perspective. It is worth examining what this means before looking at critiques of this attitude. The medical model of dementia starts from a scientific base and claims objectivity. It is concerned with dementia as disease, which immediately defines it in pathological and problematic terms.

In terms of dementia as illness:

Dementia is a syndrome which may be caused by a number of different illnesses. It is a progressive failure of many cerebral functions.
Jacques and Jackson, 2000: 1.

The different illnesses affect individuals variously. What the syndrome has in common is a decline in mental faculties. Occurrence of diagnosed dementia is low in people under 65 years old with percentages rising in each older age group above this. Prevalence is at over 30% in the over 90 year old age group (Jacques and Jackson, 2000: 3).

Causes of dementia include Alzheimer's Disease, where plaques and tangles develop in the brain and interfere with the transmission of messages sent between neurones, and multi-infarct or vascular dementia caused by a series of strokes affecting the supply of blood to the brain.

Other illnesses include Lewy body dementia, Parkinson's disease and Pick's disease. Tumours, repeated head injuries, alcoholism (causing Korsakoff's syndrome), AIDS, Creutzfeldt-Jakob disease (CJD), vitamin deficiency and Binswanger's disease can also cause dementia or dementia-related conditions (Berrios and Freeman, 1991; Gubrium, 1986a; Jacques and Jackson, 2000). Some of these conditions are reversible or may abate if the cause is removed. This would be dependent on early diagnosis and treatment. Most, including the two most common, Alzheimer's disease and vascular dementia, are not reversible. In these medical terms, dementia is caused by degenerative diseases, which can only be seen in terms of decline.

At the start of my investigation for this study, I contacted various sources to gain background information, one of which was a group that offered support and advice to people with dementia and their carers. After I had explained what I was doing, the advisor immediately told me that the very first thing I should do would be to view a video called 'Brain and Behaviour'. This video is described as being 'about how dementia as an illness affects brain functioning' (Publications List, Dementia Services Development Centre, 2001). I have not watched this video and am disturbed that advice of this sort should be given to carers, or people who have dementia. What it does illustrate is that even for a group sensitive to the needs and wishes of carers and people with dementia, it was accepted that the medical model forms the only basis for understanding dementia. My main objection to viewing the illness of dementia before anything else was that it might

influence my social view of people with dementia. In a sense, I feared that it would label people with dementia as diseased.

As will be discussed in Chapter 3, different actors have different objectives in labelling people as having dementia. Carers may be seeking an explanation of unusual behaviour. People labelled as mentally ill envisage collusion in the diagnosis procedure between family and health professionals (Goffman, 1991). But carers seek an explanation for what may be considered as unusual or changed behaviour, and this is often satisfied by diagnosis.

The benefits of labelling of dementia are not so clear for people thus labelled as they are for their families. There is also a danger that, once labelled, all behaviour will be attributed to dementia. As Cheston and Bender point out 'a diagnosis identifies an individual as a member of a specific group of patients' (2000: 50). They also say that 'the process whereby a diagnosis is reached is inevitably a subjective one carried out by fallible human beings' (Cheston and Bender, 2000: 50).

The problem of the disease model is in the way we perceive the person labelled as having dementia. The prospect of decline is expected, as is incompetence, and the person does indeed appear lost to the disease. Framing dementia research within the medical model thus obscures the person behind the disease, and guides the way that dementia is perceived. It has been criticised for this:

... the person with dementia is often relegated to the status of object rather than legitimate contributor to the research process.
Cotrell and Schulz, 1993: 205.

Seeking the subjective perspective, is one step towards redressing this imbalance.

The medical model undoubtedly informs commonsense understandings of dementia, as seen in fictional accounts which include dementia, and which have already been discussed. Challenges to the medical model of dementia have been made as they have in other areas of research. A review of these will move us further towards a social model of dementia.

Learning from disability studies

The fields of social research on dementia, and that of gaining the subjective view of dementia, are still relatively new compared to other areas of research. There may be valuable lessons that can be learnt from these areas, which may help to inform social research on dementia.

In the area of learning difficulties, strategies have been developed to help empower people. Duckett and Fryer (1998) and Stalker (1998) have employed people with learning difficulties directly in the research process, in an attempt to aid empowerment. Not only is the subjective view of learning difficulties gained, but it also becomes a part of setting the research agenda.