UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

SCHOOL OF PSYCHOLOGY

Well-being in dementia: case study examination of the importance of interactions with the carer

by

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Volume one

In memory of my Mum, Hazel Carr
and for Pa, Nick and Vlad, my best friends

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

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WELL-BEING IN DEMENTIA: CASE STUDY EXAMINATION OF THE IMPORTANCE OF INTERACTIONS WITH THE CARER

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Many people try to present their best side to the public world; people with dementia are no exception. Carers may find this infuriating as doctors, nurses or social workers may never see the person's more 'difficult' side:

"Coming up to me the hostess says: 'Isn't Iris wonderful?' She sounds surprised, perhaps thankful that there is no squeaking or gibbering going on. I am conscious of a base sense of annoyance, even exasperation. People who see Iris on such occasions assume there must be nothing much to worry about. Suppose I were to say to our hostess, 'You should see how things are at home'. Thank goodness one cannot or does not say things like that at parties."
(taken from Iris, by John Bayley)

Researchers, too, may only spend short periods of time observing or questioning people with dementia and their carers. This thesis sets out findings from a different approach to exploring their day-to-day lives. Here the researcher made extended stays of up to three days with people with dementia and their carers and repeated these visits several times over the course of 30 months. Using a case study approach for analysis the researcher looked at psychosocial aspects which may affect the person with dementia's well-being, in particular interactions with their carer, verifying previous findings reported in the literature. As well as using pre-existing measures for well-being the researcher also employed Dementia Care Mapping, for the first time, in a community setting.

As well as studying interactions, this thesis questions the motivation behind the carer's style of care. In particular the carer's perception of what it may be like to have dementia is explored. Here the notion of social death, death of the 'person' before biological death, is investigated as a possible causal factor. As previous work on social death was limited a measure was devised by drawing on a thematic analysis of six biographies written by carers of a relative with dementia.

The reader is introduced and immersed in the lives of five couples who have been affected by dementia. Such an emotionally charged subject cannot fail to touch the researcher or reader alike. Reflexivity in research is one way of dealing with this. Throughout the thesis the researcher lays bare her thoughts and feelings and how they may affect her research for the reader to make the ultimate decision.

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Volume one

Acknowledgements

My journey to complete a PhD began back in 1996, with my MSc. My supervisor then and now, Professor Peter Coleman, has been a rock throughout. I wish to thank him enormously for his inspiration, support and guidance with my studies, and also for his kindness and understanding during my darker days.

I also wish to thank Professor Steven Sabat, who has taken time to talk to me about my work and to offer guidance. His kind e-mails always motivated me and for that I am most grateful.

I single out the late Tom Kitwood for a special mention. It was his lecture at Southampton University that first drew my attention to dementia. His infectious enthusiasm for the subject is conveyed in his writing and has been an inspiration to me throughout.

To work on and be awarded a PhD has been a long term ambition of mine. I would not have managed to make the journey without the support of my best friends. Firstly Pa, one of the few people who really understands how I think and feel, who has helped me through the 'black dog' days and enjoyed the euphoria at the other side. Nick, my long suffering partner who has shown unfaltering belief in me, and finally, last but by no means least, Vlad, who has always rooted for me and been there for me, despite the miles between us.

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Chapter one

Introduction

Psychosocial factors in dementia

This thesis details research examining psychosocial factors which may affect the well-being of people with dementia living in their own home with a carer, specifically considering their interactions. A case study approach is used to explore, in some detail, the lives of five couples in this situation. By making repeated and extended visits of up to three days over the course of two and a half years, using participant observation, the couples' day-to-day lives have been explored in a unique way.

Pre-existing ideas about key factors implicated in well and ill-being taken from Kitwood (1997) and Sabat (2001) were used to guide the data collection during observation. Additionally Dementia Care Mapping was employed, for the first time, in a community setting. As well as observing interactions between carers and their relative with dementia this thesis also sought to question what may underlie the carer's style of interaction, specifically by looking at the carer's perception of what it may be like to have dementia. In order to investigate this complex area a diary pilot study was conducted, and is detailed in this document. The results of this study lead to a thematic analysis of six biographical accounts of living with someone with dementia, including John Bayley's 'Iris' (Bayley 1998). This analysis helped to unravel the complex nature of the carer's perception and finally to the production of an interview schedule which was used with the carers from the five couples.

Structure of the thesis

Firstly the rationale for my research is provided in the remainder of chapter one. The literature review, detailed in chapter two, looks in depth at the work of two key researchers in psychosocial aspects of dementia: Tom Kitwood and Steven Sabat. The review charts the emergence of this area of work by showing how the dominant biomedical model of dementia has been challenged. Finally some significant gaps in the psychosocial literature are exposed and the foundations for this research laid.

Chapters three and four set out the methodology used within this study. Firstly chapter three details the rationale for using a case study approach, and then chapter four introduces the reader to participant observation as a key method used within the case study approach. All measures used within the case study are taken from pre-existing research with the exception of the measurement of the carers' social death beliefs and associated behaviours. Chapter five charts the thematic analysis of biographies written by carers, which guided the observation and led to the development of an interview schedule.

Chapter six narrates the case studies, introducing the reader to Mr and Mrs Woody, Mr and Mrs Dudley, Mr and Mrs Archer, Mr and Mrs Reed and Mr and Mrs Jackson. The data collected during the extended visits over two years is necessarily large. For this reason summaries are presented within chapter six, but the interested reader is alerted to the full and detailed data within the second volume of this thesis. Finally chapter seven concludes the findings and suggests areas for further work.

Rationale for the research

Dementia: from biomedical to psychosocial

Estimates for prevalence of dementia vary across studies. The difficulty in measurement is compounded because a certain diagnosis of dementia cannot be made until post mortem, hence diagnosis must be made on clinical symptoms alone. (Cheston & Bender 1999a) estimate that approximately 670,000 people in the UK have some form of dementing illness. Demographic changes resulting in an ageing population will increase these figures as we move through the 21st century. This marks out dementia as a key area for research. Almost every week the newspapers herald a hopeful headline in the search for prevention or cure. For example, *'Education can curb Alzheimer's'* (The Daily Telegraph, June 24 2003). The wealth of studies seeking a cure demonstrate the prevailing approach takes a biomedical standpoint. It proposes that there are established organic diseases which account for the majority of cases of dementia in older people, with, broadly, Alzheimer's disease accounting for 50%, multiple infarctions accounting for 10-15%, and a mixture of the two accounting for 10-15%. Although the initial causes of dementia are still unknown, the dominant model sees the declining cognitive powers of the person with dementia as mirroring the deterioration of their brain tissue and as an inevitable result of having the organic disease. This deterministic view, which took centre stage from the 1970s, provides little hope for the person with dementia or their relatives. However the earlier part of the century saw a more open view, with various studies suggesting an interaction between psychological and neurological processes. More recently there has been a re-emergence of psychosocial approaches to dementia. For example (Cohen 1991), (Sabat & Harré 1992) and (Cotrell & Schulz 1993) adopt the approach of studying dementia from the subjective viewpoint of the person with dementia. Many more researchers, (Kitwood 1990), (Sabat 2001) and (Cheston & Bender 1999b) for example, are attempting to link the psychosocial and bio-medical factors, challenging the deterministic bio-medical model and arguing that neurological changes alone are insufficient to explain how the disease occurs and progresses in specific cases. This new area of research has interesting implications for dementia care, since it places importance on factors within the person's environment to their well-being. A detailed review of the emergence of this approach is reported in chapter two.

The person in dementia research

Much of the pioneering work in this new area has been carried out by Tom Kitwood and his Bradford Dementia Group. Kitwood places emphasis on the person with dementia, as a human being and not just a recipient of the disease, and considers how these psychosocial factors can affect their ‘personhood’. He identifies five human psychological needs for the maintenance of personhood; comfort, attachment, inclusion, occupation and identity, which interweave together and are all encompassed by the central need for love (Kitwood 1997). He suggests that at times of pressure or vulnerability - and for people with dementia this may be all the time - these needs surface and take on a special importance. Humans, as innately social animals, require the interaction of others to fulfil these needs. This takes on a particular relevance for people with dementia who may rely heavily on others for their daily care. Kitwood has found that it is possible for people with dementia, who score very low on cognitive tests, still to function fairly well as persons. In other words, despite failing mental ability their personhood has been maintained. This, he believes, is in part due to the person’s psychological needs being met as a result of more positive and meaningful interactions between the person with dementia and their carers.

(Sabat 2001) echoes Kitwood’s work by noting that standard cognitive tests for dementia does not give a full picture of the person’s intact abilities as they measure individual, specific aspects of cognition. He cites the case of Dr B who, despite scoring very low on standard tests was still able to judge social situations, making relevant responses, indicating the presence of intact brain systems allowing for this.

In looking at how interaction with others can affect personhood, Kitwood (1990 and 1997) developed his theory of malignant social psychology. This suggests that people may interact in ways with the person with dementia that, although have no mal-intent, nevertheless serve to erode the personhood, and hence well-being, of the person with dementia. These deleterious effects in turn result in a change in the person with dementia's behaviour which encourages further malignant social psychology and produces a cycle of decline.

(Sabat 2001) works with (Brody 1971) notion of 'excess disability' – i.e. *'the discrepancy that exists when a person's functional incapacity is greater than that warranted by the actual impairment'.* Sabat links this notion of excess disability and Kitwood's malignant social psychology by suggesting that the latter follows on from the former. This key area will be further explored in chapter two.

There has been some recent research looking into the beneficial effects of positive and meaningful interactions for example, (Bell & McGregor 1991) and (Sixsmith, Stilwell, & Copeland 1993). The majority of studies looking at the effects of care on people with dementia have been carried out in residential or nursing homes. However it has been estimated that approximately 80% of people with dementia live in their own homes, highlighting the need for research in this area. It was with this need in mind that the research detailed in this thesis evolved. The research examines psychosocial factors which may contribute to the well or ill-being of people with dementia who are living in the community with their primary carer.

Social death and dementia

A link can be seen between style of care and the person with dementia's well being. But what might affect the carer's style? The key area to be explored by this thesis is the carer's perception of what it may be like to have dementia. One of the problems with a person-centred approach to dementia care is that some carers do not perceive the person with dementia as a person any longer. This 'social death' may be seen as offering a protective function for the carer, for example (Lewis 1998) suggests that to preserve good memories of the person with dementia their spouse may draw a distinction between the person before and after the onset of disease. This may take the form of seeing them as an 'empty shell', 'not the person I married' or even 'dead'. This may help the carer to mourn their loss, but where does this leave the person with dementia?

Not all carers adopt this approach, (Jenkins & Price 1996) quote a carer, *'somewhere deep inside that shell – Jim is still there.....I have to keep believing that, else I couldn't go on putting up with this nightmare'.* We cannot question the immense difficulty carers have looking after their loved one with dementia, but is their perception of what it may be like to have dementia, and the question of social death the key? This thesis explores these issues in order to provide an answer to this question. The nature of perception and social death are dealt with in more detail in chapter five.

Participant observation: a key methodology

"Coming up to me the hostess says: 'Isn't Iris wonderful?' She sounds surprised, perhaps thankful that there is no squeaking or gibbering going on. I am conscious of a base sense of annoyance, even exasperation. People who see Iris on such occasions assume there must be nothing much to worry about. Suppose I were to say to our hostess, 'You should see how things are at home'. Thank goodness one cannot or does not say things like that at parties." This quote from John Bayley's book, Iris, (Bayley 1998) explains one of the problems with research with people with dementia. All of us can put on an act for short periods of time, and people with dementia are no exception. Thus research where only short periods of time are spent with the person with dementia and their carer are not always truly representative of the day-to-day lives. As Judy Seegmiller, who cared for her husband, Al, neatly puts it: *"No one really understands until they spend extended periods of time with the person including the nights".* (Seegmiller 2000).

Breaking new ground on research with people with dementia, this study uses participant observation as a main research methodology for exploring their day-to-day lives. Staying with the participants for up to three days at a time, the researcher was able to witness first hand some of the problems, and some of the good times, previously uncaptured by research.

Dementia is an illness which, although terminal, for many may have a protracted course taking a number of years from diagnosis to death. For this reason a longitudinal design was used to observe any possible changes in interaction and outcome for the participating couples. Within the time constraints of a PhD a time-scale of approximately 30 months was used for data collection.

A case study approach to dementia

Since it was thought that many psychosocial factors may impinge on the well or ill-being of a person with dementia the study required a methodology equipped for dealing with data collection at this level. A case study methodology was therefore chosen because it is a method which provides an account of why a person behaves as they do in a given situation. Additionally it allows for both personal and situational factors to be taken into consideration in accounting for that person's behaviour, and is an important tool in psychological investigation in both the development and validation of theory. This is shown by (Coleman, Ivani-Chalian, & Robinson 1999). The case study method also allows for the study of an individual's behaviour within the context they find themselves in - in this study, to look at the well-being or ill-being of the person with dementia in terms of their interactions with others. Further details of the methodology and procedures used are detailed in chapter three.

Research questions addressed

1. What is day-to-day life like for someone with dementia living in their own home?
2. What types of interactions are they having with their carers, and what effect might this have on their well-being?

3 Can Dementia Care Mapping (DCM) be used to investigate activity and well-being for people with dementia living in their own homes?

4 How do their lives change over time?
   a. Interactions
   b. Nature of interactions
   c. Well-being
   d. Symptoms of dementia

5 What is the carer's perception of what it might be like to have dementia?

6 What are the carer's (a) beliefs, (b) behaviours towards their relative's possible social death?

Reflexivity and research

This research utilises a case study approach and participant observation and aims to be rigorous in its approach. My background in a scientific research area as an analytical chemist now leaves me seeking rigor in both quantitative and qualitative methods alike. However since changing from chemistry to psychology I have become aware of, and see the benefit in, making the research process transparent. One way to do this is by laying bare the thoughts and reflections of the researcher during this process. In research where the researcher and participants live closely together and get to know each other over a period of time it is inevitable that the researcher cannot remain 'impartial'. Previous experiences, thoughts and feelings cannot be left outside the door only to be collected when the observation ends. I may have hoped to do that once, but I now know that it is not possible. Hence I have recorded my reflective notes as an important part of this thesis.

Chapter two

Literature review

Introduction

This chapter details the work of two researchers within the field of dementia: Tom Kitwood and Steven Sabat. The work of these researchers is key to the focus of this thesis in exploring the psycho-social aspects of dementia. In charting the history of dementia to the present day this chapter highlights how the dominant biomedical model has, in recent years, been challenged. The critique, looking at the importance of psychosocial factors, includes an opposing end of the ideological spectrum with a social constructionist approach. Whilst this chapter acknowledges the ideas presented by this model of social psychology it is then argued that a pragmatic approach is required. It is here that the now classic works of both Tom Kitwood and Steven Sabat take centre stage and provide an introduction to continuing work in this area. The focus is then narrowed to introduce one aspect of the psychosocial arena taking a central position in this research: social death. This under-researched area is explored and linked to the aims of this thesis. However, in order to set the scene for the birth of this topic area from the author's perspective the chapter begins by looking at how the author first became attracted to the area of dementia.

My first interest in dementia

'PERSON with dementia not person with DEMENTIA'. A sign on a door which first aroused my interest in the field. I was doing an MSc in Health Psychology and had yet to decide on a topic for dissertation. My initial degree and subsequent 14 year career in analytical chemistry set me with a positivist approach to research. I felt that I should choose a subject with which I had no personal experience lest this may add to subjective bias in my study. Tom Kitwood's talk fitted the bill. His, now legendary, style of presenting captured my imagination as an area where psychology could be important. His ideas about the relevance of personhood in dementia care, coupled with his pragmatic approach to this area struck a chord. Learning that he too had initially trained in chemistry finalised my choice. I set about looking at psychosocial aspects of dementia for my dissertation.

This naïve introduction to dementia care has, for me, developed into a changing perspective on both epistemology and accompanying methodology. My journey through that process is charted in this thesis, and begins with a summary of Tom Kitwood's work.

A summary of his work

Tom Kitwood's first direct contact with dementia was in 1975 with a woman he knew as 'Mrs E'. This was ten years before he began work in the area, and by his own admission he was, like others, *'completely seduced by the prevailing view: dementia is a 'death that leaves the body behind''.* (Kitwood 1997). He later termed this prevailing view, *'the standard paradigm'*, referring to the medical model which has dominated throughout the past century.

On moving to work in the field of dementia he began to question his initial view. On spending time with people with dementia in formal care settings, and with the help of his background work on ethics he became aware of the many ways in which they were treated as non-persons. These observations became the basis for his work on malignant social psychology.

Kitwood set about writing a series of papers in Ageing and Society outlining his thoughts.

In the first of these papers (Kitwood 1989) suggests that the medical model of dementia, suggesting a straightforward linear, causal relationship between neuropathology and dementia is insufficient. He concludes that psychosocial aspects, such as interactions with others, may be of great importance and suggests that the process of dementia may be represented thus:

$$\begin{gathered}\underline{\psi \equiv b}\\ B^d, B_p\end{gathered}$$

where the person with dementia's psychology, their psychological experience, (ψ), directly corresponds with the functional state of their brain (b). These in turn are affected by both neuropathology (B_p) and the brain structure established through development and learning (B^d). This would mean that a change in the person's well-being, perhaps as a result of poor interactions with others which serve to destroy personhood (now known as 'malignant social psychology'), may affect the neuropathology. Similarly a decline in brain neuropathology could be compensated for by an increase in their well-being. In other words, the process of dementia could be viewed in a systemic way with neuropathological and psychosocial factors affecting one another. This dialectic model allows for a change in one factor to affect another but does not need a causal link to be made thus avoiding 'chicken and egg' arguments. Additionally it allows for the individual variation observed within people with dementia.

I wonder if Kitwood's original training in chemistry had influenced him to present his ideas in this mathematical notation form. Whilst he may also have been trying to appeal to those within the circles of the medical model, by giving it some 'scientific credibility', I feel that this does not add anything to his ideas nor does it sit easy with those from a purely social science background. However, he was a hybrid of both and his work has had the difficult task of persuading people working within both medical and social elements of dementia care that the solution lies within a marriage of the two. The actual substance of his idea, however, does have merit. It both offers hope to an area which would previously have denied one and also may offer an explanation as to the disparity in individuals between brain pathology and presenting behaviour.

He expands on this idea in his second paper in this series, (Kitwood 1990) firstly by offering a 'note on method'. Here Kitwood is again trying to appeal to the medical world by providing a rationale for using anecdotal observation and semi-structured interview. He then introduces the idea of malignant social psychology explaining that the ten elements he proposes here are ways of behaviour towards someone with dementia which may serve to diminish their personhood. This behaviour may not be intentional but results as being part of the culture dominated by the medical model.

1 Treachery
Some form of dishonest representation, trickery or outright deception is used by others, in order to get the dementia sufferer to comply with their wishes.

This is a commonly used element though it can, as they all can, differ in severity. Driving an old woman to a residential home but telling her you are taking her *'out for a drive'* being at the severe end whilst a carer tired of being asked *'when is lunch?'* replies *'in five minutes',* even though it may be hours away, may represent a lesser level.

2 Disempowerment
Things are done for a dementia sufferer even though he or she is able to do them, albeit clumsily or slowly. There is a consequent loss of confidence, a de-skilling process, a diminution in the sense of agency.

3 Infantilisation
This is a more extreme and persistent form of (2) but accompanied by messages, subtle or otherwise, that the dementia sufferer has a mentality and capability very much like that of a young child.

4 Intimidation
The dementia sufferer is made afraid by such processes as head-scans or psychological assessments, these being carried out in a somewhat impersonal way by professionals who are powerful and competent. Sometimes intimidation includes threats or actual physical assault.

5 Labelling
A confused elderly person is given a diagnosis such as 'primary degenerative dementia' or Alzheimer's disease. Expectations of progressive decline and derangement are set up and a self-fulfilling prophecy comes into play. The sufferer is treated differently, in many subtle ways, from this time forward.

This element is often used where dementia forms the central perception others have of the person with dementia and it is used as a basis for explaining that person's behaviour and for interacting with them.

6 Stigmatisation
This is an aspect of labelling, but it also carries connotations of exclusion. The dementia sufferer becomes strange, alien, a diseased object, an outcast.

7 Outpacing
It seems that a dementia sufferer often functions mentally at a much lower rate than those who have no impairment. However, caregivers often continue to go at their normal pace and so fail to establish good contact.

8 Invalidation

In order to feel alive, grounded, in touch, we need our experience – especially emotions and feelings – to be understood, accepted by another. We also need the kind of response that takes our experience into account. All this may be described as the validation – making real or valid – of our subjectivity. Invalidation occurs when the subjectivity of the dementia sufferer is ignored or overlooked.

9 Banishment

The dementia sufferer has become intolerable to others in some way. He or she is removed from the human milieu, either physically or psychologically, rather like being 'sent to Coventry'. The result is a deprivation of sustaining human contact.

10 Objectification

The dementia sufferer is not treated as a person: that is, as one who is an autonomous centre of life. Instead he or she is treated in some respects like a lump of dead matter to be measured, pushed around, manipulated, drained, filled, dumped etc.

Some of the main categories of malignant social psychology are used in Dementia Care Mapping to observe the patterns of care for dementia patients (Bradford Dementia Group 1997a). However, although Kitwood declares the malignant social psychology to be unintentional some researchers, for example (Watson 1998), take exception to the suggestion that the decline observed in people with dementia is due to the way that society has treated them or the way that they have been cared for.

The remainder of the paper sets out his dialectical model of dementia. Here he details how social psychological aspects of a persons life, such as the effects of malignant social psychology, can erode personhood which in turn affects their neurological impairment. He pre-empts critics of this approach by suggesting that if this new theory is closer to the actual process than the linear causality medical model then no change in a person's social psychological life will change the impairment. In other words, good psychological care, if his model is correct, will result in an improvement in the person's functioning. He notes that there has been anecdotal evidence to support this.

Together with his colleague, Kathy Bredin, he wrote the last of these particular series of papers outlining 'person centred care' which detailed their thoughts on the preservation of personhood as being central to this 'new culture of care' (Kitwood & Bredin 1992a). In this paper they note the absence of a theory of dementia care and offer their own. This theory highlights the centrality of personhood and its maintenance for continued well-being in dementia. They cite the importance of 'the other' in dementia care in terms of interactions, naming malignant social psychology as the cause of ill-being but then turning to a more positive focus which considers how good interactions can help to increase well-being by maintaining personhood.

In looking to measure the maintenance of personhood they detail 12 indicators of well-being:

1. The assertion of desire or will
2. The ability to experience and express a range of emotions (both 'positive' and 'negative')
3. Initiation of social contact
4. Affectional warmth
5. Social sensitivity
6. Self-respect
7. Acceptance of other dementia sufferers
8. Humour
9. Creativity and self-expression

10 Showing evident pleasure
11 Helpfulness
12 Relaxation

An example of social sensitivity was highlighted in one of my earliest visits to a person with dementia, May. As I put my cardigan on to leave my shoulder (a victim of an earlier whip-lash injury) made a loud crack noise. May noticed this and rubbed my shoulder gently exclaiming 'sore!'. I have often witnessed humour in my visits to people with dementia who, despite their dementia, are living in high states of well-being.

These indicators of well-being were further researched, and categories refined, by the (Bradford Dementia Group 1997b), and are used within this thesis in the case study analysis.

These ideas formed the basis for Kitwood's social-psychological theory of dementia and heralded the birth of the Bradford Dementia Group, cementing what was to become a major step forward in the psychology of dementia care.

His prize-winning book, (Kitwood 1997), collates together and builds on his earlier ideas. For example, his original list of 10 elements of malignant social psychology are expanded to 17 to also include:

11 Ignoring
Carrying on, in conversation or action, in the presence of a person as if they were not there.

12 Imposition
Forcing a person to do something, overriding desire or denying the possibility of choice on their part.

13 Withholding
Refusing to give asked-for attention or to meet an evident need.

14 Accusation
Blaming a person for actions, or failures of action, that arise from their lack of ability or their misunderstanding of the situation.

15 Disruption
Intruding suddenly or disturbingly upon a person's action or reflection, crudely breaking their frame of reference.

16 Mockery
Making fun of a person's 'strange' actions or remarks; teasing, humiliating, making jokes at their expense.

17 Disparagement
Telling a person that they are incompetent, useless, worthless, etc, giving them messages that are damaging to their self-esteem.

Kitwood sees the maintenance of personhood as key to well-being in dementia and further expands on these ideas in his book. He identifies five human psychological needs; comfort, attachment, inclusion, occupation and identity, which interweave together and are all encompassed by the central need for love. He suggests that at times of pressure or vulnerability - and for people with dementia this may be all the time - these needs surface and take on a special importance. Humans, as innately social animals, require the interaction of others to fulfil these needs. This takes on a particular relevance for people with dementia, who may rely heavily on others for their daily care.

An example of the maintenance of personhood is given by (Wright 1993) where she reports that some carers preserved the 'illusion of involvement' by preparing a cheque but letting their spouse with dementia sign it. (Miller 1987) cites a similar strategy used by caregiver wives to preserve their husband's self esteem.

Kitwood sets out elements of 'positive person work' which help maintain the personhood by understanding the meaning of behaviours from the perspective of the person with dementia. These elements consider various positive interactions which may occur between people with dementia and their carers.

The first 10 interactions form the basis of good care:

1 Recognition
2 Negotiation
3 Collaboration
4 Play
5 Timalation
6 Celebration
7 Relaxation
8 Validation
9 Holding
10 Facilitation

There are also a further two interactions where the person with dementia plays the leading role:

11 Creation
12 Giving

These type of interactions are highlighted during dementia care mapping where they are recorded and referred to as positive events.

However, the person centred style of care has only recently emerged in the vast history of dementia research. This next section traces this background and locates the person centred care in time. It also further considers some of the critiques of Kitwood's work in more detail.

Dementia: a history of biomedical dominance

At the beginning of the twentieth century most cases of dementia were linked to vascular pathology. The exception came in 1906 when Alois Alzheimer reported a case of a woman with symptoms of dementia whose brain on post-mortem showed signs of neurofibrillary tangles and senile plaques. Emil Kraeplin brought this case to public attention in his psychiatric text book in 1910. This marked the end of the distinction between dementia and ageing as the cases of senile dementia were then subsumed under the label of Alzheimer's Disease. Today a pre-morbid diagnosis of Alzheimer's Disease is still not possible since it is only at autopsy that the brain changes characterising Alzheimer's Disease can be identified. The diagnosis of probable Alzheimer's Disease is one of elimination and is given when the person is showing slowly progressing cognitive impairment and no other cause can be identified.

Vascular, or multi-infarct dementia, was known to be caused by occlusion of oxygen to the brain. This can occur by arteriosclerosis, blood clots, or haemorrhages to the brain. Treatment for this form of dementia has concentrated on minimising further infarcts with blood thinning medication such as aspirin and warfarin. In searching for the cause of Alzheimer's Disease the link between possible cause and associated treatment was continued. In other words, a biological cause was felt to require a biological treatment. However, in the case of Alzheimer's Disease the causes are still not yet known. Hypotheses considered include prions, trace-metal studies, genetic studies and neurotransmitter studies. Since the cause is not yet established a cure cannot be researched and recent treatment has concentrated on re-balancing neurotransmitter levels in the brain, in particular acetylcholine. For example, Tacrine, Donepezil and Rivastigmine, three of the most recent medications, act by increasing the levels of acetylcholine available. Whilst these drugs seem to offer a temporary boost to cognitive function for some, (Knapp, Knopman DS, & Soloman PR 1994), (Rogers et al. 2000), (Corey-Bloom, Anand, & Veach 1998), their cost has led to inconsistencies in prescribing.

The biomedical approach, taken alone, currently offers little hope to sufferers and carers alike. A headline cited by (Kitwood 1997) neatly summarises the popular view:

'Alzheimer's: No cure, no help, no hope'.

Critics of this deterministic biological view have challenged this and it is to them we turn in the next section.

Brain pathology and dementia: some inconsistencies

A series of studies aiming to quantitatively assess brain pathology and dementia, the first of which took place in 1968 (Blessed, Tomlinson, & Roth 1968), cast doubt on the direct causal link between brain pathology and behaviour linked to dementia. One of the aims of the first study was to look for quantitative difference in brain pathology, for example plaque count, between older people with psychiatric disorders and 'normal' older participants post-mortem. Although, in the case of dementia, the authors found that the mean plaque count was higher than that of the controls there was nevertheless great individual variation in plaque count within the dementia group which could not be explained by differing levels of cognitive impairment. Hence, taking a critical view, one could conclude that although senile plaques are a feature of dementia, a direct linear relationship between the degree of cognitive impairment and number of plaques cannot be held. This would suggest the involvement of other factors. Similarly (Jacoby & Levy 1980) found, using computerised tomography (CT), that participants with dementia showed more evidence of cerebral atrophy than participants without dementia but again there was considerable overlap.

These research findings, as well as providing more evidence that there may be factors other than neuropathology alone operating, also have implications for diagnosis. Jacoby and Levy themselves point out that the amount of overlap between the participants with and without dementia would lead to around a 17% incorrect prediction rate. This difficulty with diagnosis has been examined in other studies. For example, (Homer et al. 1988) looked at post-mortem diagnosis of dementia in 27 patients and compared the findings to the diagnoses made while they were alive. They found that the correct diagnosis in the type of dementia had been made in only just over half of the cases. [It is also interesting, and perhaps ironic, to note that according to notes written by Alois Alzheimer about the autopsy of Auguste D. - the first patient to have been diagnosed as having Alzheimer's disease - a true diagnosis would have been a mixed Alzheimer's disease and multi-infarct dementia (Woodruf-Pak 1997)]. One case of Homer's was surprising as post-mortem showed that she had a normal brain for her age. One explanation for cases such as these is 'pseudodementia'. This is a term used to describe people who show signs of cognitive deterioration similar to those seen in dementia but because of different causes - for example depression (Arie 1983). (Jacoby & Levy 1980) affective group of participants who scored significantly lower than the controls on the memory and orientation test could be said to have 'pseudodementia'. One problem, highlighted by (Albert 1981), with mis-diagnosis from pseudodemenia to dementia is that if depression was the underlying cause then the dementia could have been reversed by treating the depression. It is, however, also interesting to note that depression is found to co-exist with Alzheimer's disease in a number of cases. For example, (Forstl et al. 1992) found depression in 27% of their sample of people with Alzheimer's disease, and their review of the literature suggests this to be a fairly typical figure. So, in almost one third of people with Alzheimer's disease there is perhaps the possibility of cognitive function appearing to be even lower because of depressive symptoms.

But perhaps the true problem lies with the inconsistency between presenting symptoms and brain pathology. For example (Lyman 1989a) reviewed a number of studies which suggest that not only is the type of dementia misdiagnosed or that people with symptoms of dementia may have depression and hence no underlying cerebral atrophy, but also that approximately 10% of healthy people who function without symptoms of dementia were shown to have Alzheimer's type brain pathology post-mortem. (Bender & Cheston 1997) also point out that it is difficult to explain using a biomedical perspective alone how dead or diseased brain cells in people with dementia produce variable levels of functioning from day to day. And although it could be counter-argued that everyone has 'good and bad days', how does the medical model account for lucid moments (Bender 1998)? These anomalous findings shed doubt on the current bio-medical approach to dementia and has encouraged some researchers to look for a different perspective in their search for these extra factors.

The rise of the person in dementia research

The psychosocial approach to the study and treatment of dementia is a fast growing area and owes many of its origins to the late Tom Kitwood, whose work in the late 1980s and 1990s began the increased interest. Although in the 1980s some progress had been made in psychosocial research this was restricted to the experiences of the carers rather than the person with dementia. For example: a review of factors affecting the well-being of carers (Morris, Morris, & Britton 1988); carer burden (Duijnstee 1992); differences between husbands and wives in terms of relationship satisfaction, distress and depression (Fitting, Rabins, & Lucas 1986); gender differences were further explored in a meta study by (Miller & Cafasso 1992).

In working with people with dementia (Feil 1982), in her validation method, acknowledged the importance of communication which affirmed the person with dementia's emotions and subsequent behaviour but research exploring this area was missing. Similarly, (Goudie & Stokes 1989) resolution therapy used validation of emotions and incorporates reflection of these using Rogerian counselling techniques. But it was Tom Kitwood's persuasive and passionate writing style that helped to redress the balance of research in returning the focus on the person with dementia to centre stage.

The Bradford Dementia Group, where Tom Kitwood was made professor shortly before his unexpected death, is testament to his work. As well as enticing followers to the cause his work has also attracted criticism from within the psychological sphere from a social constructionist approach. This next section begins by looking at the critiques and concludes that Kitwood's approach should be valued for its pragmatic nature with respect to the research detailed by this thesis.

Approaches to the study of dementia mirror approaches within mainstream psychology in consisting of perspectives which can be viewed as complementary, incommensurable or through a reductionist strategy. The biological approach has already been detailed. The social constructionist critique of Kitwood's work can also be shown to take a reductionist strategy. However, Kitwood's approach can be seen alongside the medical model as a complementary vision.

Social construction of dementia

Social scientists who reject the medical model completely, arguing for their own deterministic view from the other end of the ontological spectrum, form a group known as social constructionists. A social constructionist view of dementia questions the notion of dementia as a disease, instead preferring to view it as *'free of social constraints towards* *conformity'* (Harding & Palfrey 1997). This disease or medical model is purported by Fox (1989) (cited in (Harding & Palfrey 1997) to have been invented, thus reclassifying senility from a natural ageing process to disorder, for political reasons, attracting more research monies. The maintenance of this belief may be fuelled by our fear of old age and hope for a *'cure'* (Harding & Palfrey 1997).

Central to their debate is the idea which suggests that once diagnosed as having dementia a person is viewed differently by others, and subsequently their behaviour is attributed to the disease alone.

A pure social constructionist approach requires a radical change to society before people with dementia would benefit. Followers of the anti-psychiatry movement have tried admirably for decades to change the approach to mental health, winning only small victories rather than making sweeping changes. For example, Crow Holbeche's much publicised battle to halt his compulsory community injections in the last months of his life as a cancer sufferer, led by the Exeter Action for Respect (Mclaughlin 2002).

However it is the author's view that whilst this radical approach has laudable aims a more pragmatic approach, acceptable to the majority, will help people with dementia. Such an approach is adopted by, for example, (Kitwood 1997), (Cheston & Bender 1999) and (Sabat 2001). Whilst they make take a constructionist position insofar as they recognise the impact of society on the individual with dementia and seek an alternative to the medical model. (Harding & Palfrey 1997) acknowledge the work of these key researchers trying to raise the profile of psychosocial factors. However, they criticise this approach by noting that it is illogical to reject a medical model on the one hand and accept the need for therapy on the other. But it may be more accurate to suggest that these more pragmatic approaches do not reject the biomedical model but seek to add to it.

Psychosocial, person centred approaches – a more pragmatic view

Kitwood acknowledges the role of society in shaping our views on dementia, and the knock-on effect this has on our treatment of people with dementia. For example his malignant social psychology, detailed on page 16, he sees as originating from wider societal attitudes. However, his level of analysis concentrates on interactions between the person with dementia and others, for example their carers.

Whilst the aims of the social constructionists and critical psychologists in highlighting the plight of the person with dementia may be laudable, Kitwood's interpersonal level of approach makes it more pragmatic. Indeed, Kitwood's approach should not be seen as opposing the biomedical perspective but operating in tandem with it. He warns against the *'danger of trivialising the ravages inflicted at the neurological level in severe dementia'* (Kitwood 1993). In other words, Kitwood advocates the bringing together of both social and neurological impairment.

(Kitwood 1990) attempts to draw together elements from both bio-medical and psychosocial approaches to dementia in his dialectic model of dementia. This model suggests a straightforward linear, causal relationship between neuropathology and dementia is insufficient, suggesting that a change in the person's well-being, perhaps as a result of malignant social psychology, may affect the neuropathology. Similarly a decline in brain neuropathology could be compensated for by an increase in their well-being. In other words, the process of dementia could be viewed in a systemic way with neuropathological and psychosocial factors affecting one another. This dialectic model allows for a change in one factor to affect another but does not need a causal link to be made thus avoiding 'chicken and egg' arguments. Additionally, it allows for the individual variation observed within people with dementia. However, it may be that this dialectic approach enables us to explain why dementia has occurred from any angle we choose or link it to any life event we may elicit in discussion with relatives. This approach may be useful in explaining the reasons after the event but does it have any predictive value?

The significance of interactions

Kitwood's malignant social psychology and positive person work have already been detailed. In addition other researchers working within the person centred approaches also lend support to the importance of interactions in maintaining or eroding personhood. In particular the work of Steven Sabat.

(Sabat 2001) questions the traditional use of the battery of cognitive tests which are given to people thought to be suffering from dementia. He links this to the dominance of the medical model but criticises it on the grounds that these tests highlight what the person can no longer do. In taking a more hopeful and positive view like other person centred approaches he shifts the focus to concentrating on the persons remaining abilities. He also uses his case studies presented in his book as evidence that despite the tests suggesting that cognitive functions are eroded people with dementia are still able to complete tasks requiring these cognitive functions when considered within the every day context of their lives rather than in the impersonal and meaningless context of a hospital clinic.

For example, Dr B's reaction to meeting one of Sabat's students:

'Oh yes, that guy. I have a piece of paper', (referring to a piece of paper on which he had asked Sabat to write his name and telephone number in case he forgot his name). He asked the student her name and on repeating it several times said, *'Excuse me if I forget, but I've got this problem. Sometimes I go in small ways, but don't be alarmed. I have Alzheimer's.'* Here Sabat interprets this as meaning that Dr B shows he remembers Sabat and also realises that he has not met the student

before as he explains about his Alzheimer's Disease, hence he is able to gauge the social situation well (Sabat 2001).

In common with Kitwood, Sabat also considers the psychosocial aspects of dementia as one area in which we can make a difference whilst the medical area is being developed.

Selfhood

Sabat {Sabat & Harré 1992 47 /id} take the notion of selfhood and divide it into three parts:

Self one – which is our own perception of our continuing experience as a unitary item.

Self two – which is the mental and physical attributes we have, or have had, throughout our lives, for example, being Japanese or a teacher.

Self three – which describes the various ways we present ourselves to the world. For example we could be a strict teacher but a friendly, easy-going wife. Hence self three requires the interaction of others in order to be manifested and hence people with dementia can be vulnerable in this aspect of self. This again highlights how interactions with others are important in the maintenance of personhood – in this case self three. If a person with dementia is always seen in terms if their illness then any other aspects of their self three that they try to project will be seen in the light of dementia too.

Using positioning theory Sabat goes on to explain how the initial positioning or labelling of a person can lead us to make incorrect attributes about their subsequent behaviour. In other words, if we position a person with dementia as being 'ill' we may see their behaviour in terms of their illness when it may not be appropriate. Sabat's case studies provide illuminating examples of this in action. For example, Dr B became very upset when a group of people had a meeting in the same room that he and Sabat had met in two days earlier. This was not the usual room they met in but the day centre had been noisy and Sabat had found this, a quieter room. Positioned as 'ill' Dr B's behaviour may have been viewed as agitated. However, seen in the light of the meeting he and Sabat had two days previously, he was concerned that the room couldn't be used as he was meeting Sabat later that day. Sabat also suggests that this illustrates intact implicit memory (Sabat 2001).

Sabat's detailed case studies illustrate how a depth study of a person with dementia reveals a lot about the nature of the disease in the social (day to day) context. He ingeniously analyses the minutiae of interactions and behaviours to demonstrate cognitive functions still intact. This 'reversal' of emphasis from what is missing or no longer intact with the medical perspective to what remains in the psychosocial, person centred approach is for me an important change. For example Dr M, who had a diagnosis of probable Alzheimer's Disease, could no longer sign her name when she first met Sabat. However, on discussing her experience of word finding difficulties she described two strategies that she uses to protect herself when she cannot find the right word:

1 She tries to change the subject, *'getting the person off track'.*
2 She asks the person to *'say it differently to me'.* (Sabat 2001)).

Both these strategies may be mis-interpreted by the person as signs of (1) confusion and attentional difficulties and (2) auditory comprehension and attentional difficulties whereas, in reality, she is aware of her word finding problem and trying to hide it. He also later demonstrates Dr M's other intact abilities such as the ability to plan ahead. However, these abilities would be missed by tests favoured by the medical model since they would be carried out in a 'consultation' style setting rather than drawn and interpreted from real life situations as Sabat does.

In looking at interactions with others, Sabat describes the 'cycle of misinterpretation' which may occur when a person with dementia is positioned as 'ill'. Any reaction to negative interactions with the person with dementia will be interpreted in light of the disease rather than as a justifiable reaction against the negative interaction. This misinterpretation can lead the person with dementia's behaviour to be labelled as 'problem' and medication administered. Rosenhan's (1973) classic study where researchers gained admission to a psychiatric hospital by pretending to be hearing voices illustrates this well. The researchers, thought to be showing signs of a psychotic illness made notes during their stay on the ward. These 'field notes' were viewed by the hospital staff as further indication of their declining mental state! (Holstein 1998) cites the fictional character of Murray Wasserman (Buchanan 1989) to describe how this process may operate:

'His least and every move was watched intently by someone, not in order to see what was right about it but only to wait for him to do something wrong. With the naming of his illness, his life had suddenly become a negative reversal in which only shaded areas were observed, with all the positive images disregarded as exceptions to the darkness of his impending situation'.

Looking from the person with dementia's perspective, we can also observe the devastating effect on self esteem and identity that receiving a diagnosis of dementia has (Husband 1999).

Sabat uses (Brody 1971) concept of excess disability when considering negative interactions:

'[excess disability] is the discrepancy that exists when a person's functional incapacity is greater than that warranted by the actual impairment'.

He links excess disability with Kitwood's malignant social psychology by suggesting that excess disability is a consequence of malignant social psychology.

Sabat takes the concept of malignant social psychology further by suggesting that if we observe a person with dementia in two different social situations, one with elements of malignant social psychology present, the other without, and we notice a difference in the person with dementia's behaviour between the two situations we can assume this difference is due to the effect of the malignant social psychology rather than the neuropathology. This method also lends further support for the existence and effect of malignant social psychology, for if the person with dementia were oblivious to the malignant social psychology then there would be no difference observed in behaviour between the two settings.

Sabat notes the presence of excess disability in the case of Mrs R who showed far greater abilities when at the day centre than when with her husband. For example, he would cut her food up for her at home whilst she ate without aid at the day centre. He links the presence or absence of excess disability, the consequence of malignant social psychology or positive person work, to the presence of others.

Like Kitwood, Sabat too turns his attention to a more positive approach by shifting the focus to looking at the remaining abilities of people with dementia. Here he uses (Kitwood & Bredin 1992b) indicators of relative well-being and adds to this by also considering the maintenance of self esteem.

The maintenance of self esteem

Sabat suggests that to see a person with dementia in terms of what they cannot do (for example, cognitive tests) can only weaken their self esteem. However, to view a person in terms of their remaining capacities may also help to preserve some self esteem and hence enhance personhood. He cites the case of Dr M who, after being sent to a speech therapist by her husband in the hope that it may help her word finding problems, told Sabat that she didn't want to be *'going always to see people to see what's wrong with me!'* (Sabat 2001). He also shows how Dr B, a retired professor with Alzheimer's Disease, maintained some self esteem by seeing himself as a *'scientific collaborator'* in Sabat's work. Dr B asked the day centre staff to put the times of his meetings with Sabat on the notice board for others to see. This also illustrates how some knowledge of the person's life history can also help in maintaining their self esteem. *'To know a person is to know their identity'* (Coleman 1997). Keeping even small parts of the story alive will help the person with dementia to maintain self esteem, but this requires the positive cooperation of others and highlights the essential importance of interactions. This has been demonstrated by (Gibson, Marley, & McVicker 1995) using case studies.

However (Thorngate 1999), in his critique of Sabat's paper on self esteem (Sabat et al. 1999), suggests that Sabat makes a fundamental attribution error in looking at his cases. For example (Sabat, Fath, Moghaddam, & Harré 1999) suggests that Dr B's refusal to take part in the games, such as bingo, played at the day centre is his attempt to retain self esteem. (Thorngate 1999) argues that an alternative explanation might be that he didn't know how to play and was embarrassed, or simply didn't enjoy the games. However, when seen in the light of the whole of the case study of Dr B including information about his previous occupation and nature of interactions with others (Sabat 2001), it could be argued that this is a fair interpretation considering all the evidence. Thorngate's critique is based on his limited evidence of one act. This also demonstrates the value of case studies in building up corroborating evidence from a variety of sources for why a person behaves as they do.

One might question if Sabat's participants were 'typical' Alzheimer's Disease sufferers. Two were academically high achievers and it could be argued that this may enhance any remaining cognitive functions. Sabat predicts this criticism and counters it by noting that they both showed scores on standard tests of cognitive function which indicated a moderate to severe level of dysfunction. This demonstrates how such tests do not provide us with a complete picture of a person's intact functions. Sabat further feels that their stories serve to help us give the benefit of the doubt to people with dementia by positioning them as *'having something to say'*.

Further evidence for the importance of psychosocial factors

The literature review thus far has concentrated its focus on what are, in my view, the two key workers within this field. However, there are a number of researchers who are also working within this field and who have produced further evidence supporting importance of the psychosocial aspects of dementia.

A series of classic studies in gerontology by (Schulz 1976), (Rodin & Langer 1977) and (Schulz & Hanusa 1978) demonstrated the beneficial effect of having perceived control over even small aspects of the environment for older people. These studies highlighted some of the problems in caring for older people in residential homes and how small changes can affect well-being in either direction. People with dementia may be particularly vulnerable to change within the environment. (Cotrell & Schulz 1993) believe that taking a purely medical perspective of dementia can lead to viewing people with dementia as *'passive individuals who are succumbing to deficits'* rather than *'important actors responding and adapting to the disease'*. Following on from this (Bredin, Kitwood, & Wattis 1995) found that the quality of life of patients declined severely following a merger of two long stay wards. The authors suggest that this may, in part, be due to unmet needs of both staff and patients in turn affecting the quality of interactions. It may also be that the nature of dementia necessitates that people with dementia need to feel secure in a familiar place and are psychologically vulnerable when it comes to change. Evidence for a change in environment resulting in measurable changes in brain biochemistry serves to provide an important link between the medical and psychosocial models of dementia. The work of (Karlsson et al. 1988) aimed to link the increased well-being of people with dementia following an increase in activities in their care setting with changes at a brain biochemistry level. They found that this positive change in environment did increase the levels of certain brain biochemicals in cerebrospinal fluid (CSF) in the experimental group as well as lowering their anxiety and depression levels and improving motor function. However, this sort of study is not without its critics because of the invasive nature of obtaining CSF.

(O'Dwyer & Orrel 1994) attempts to link stress with deterioration in dementia via the hypothalamic-pituitary-adrenal (HPA) axis. The hippocampus, a key area in memory and one affected pathologically in Alzheimer's Disease, forms part of the HPA axis. This model could show how stress, perhaps due to negative interactions, could affect brain pathology. (Orrell & Bebbington 1995) demonstrates that people with dementia react to stressful events in the same way as cognitively intact humans, strengthening the case for this model.

Taking a wider view of the environment to include dominant societal attitudes (Levy & Langer 1994) have shown how this can in turn affect our memory. Their study used participants from American deaf and Chinese cultures, which were assumed to be removed from American (hearing) culture and compared memory in the three groups in both old and young. The American deaf and Chinese groups showed no differences between old and young whereas the American hearing group showed the stereotyped view of short-term memory decline in their older group. This phenomenon could be applied to people with dementia in terms of a negative environment. Indeed, Chinese views of dementia are much more positive and this has obvious benefits to both carers and sufferers alike (Ikels 1998).

The ‘management’ of behavioural disturbances in dementia care also provides us with an insight into the deterministic nature of the biomedical model. For example, antipsychotic drugs are often used to control behavioural problems in dementia. (Helms 1985) reviewed studies looking at different antipsychotic drugs and concluded that many have beneficial effects which justify their use. However, he also highlighted a number of studies which revealed adverse effects in their use in as high as 90% of the participants but notes that details on the severity of reaction are not provided. However (Cohen 1991) hypothesises that the onset of behavioural problems in dementia are as a result of the inability of the patient, family and health professionals collectively to cope with the declining cognitive functions and the resulting reactions to it. (Kitwood & Bredin 1992b) suggest that behavioural disturbances may manifest themselves at the point where the person is in a *‘shattered’* state. That is they are surrounded by people but *‘desperately alone in the sense of lacking subjectivity’*. (Cotrell & Schulz 1993) suggest that these behaviours may be an attempt to avoid a *‘stigmatising identity’*. This may reinforce the need to understand the subjective experience and link this to care and treatment regimes. For example (Bell & McGregor 1991) view psychotropic drugs as *‘merely serving to muddle the thought processes’* and have demonstrated increases in well-being of patients who have had their medication discontinued on admission to Bell and McGregor’s nursing home. Rather than controlling behavioural problems with medication Bell and McGregor see these behaviours as a expression of unmet needs which should be investigated. (Shomaker 1987) also advocates exploring the meaning of what appears to be unusual behaviours. She found that some can be re-interpreted in the light of their past history leading to reduced frustration and greater insight for the carers. Similarly, (Goudie & Stokes 1989) have shown that greater insight can help in providing solutions to some of the confusion people with dementia feel in using resolution therapy.

Taking a more positive view of dementia, in contrast to the deterministic medical view, may allow for positive person work and a reduction in elements of malignant social psychology (Kitwood 1997). Examples of this kind of care having positive effects is gradually making its place in the literature. For example (Nairn 1995) reports on a study where the introduction of activities into a nursing home, using life histories as a guide to residents' interests, lead to a measurable improvement in resident apathy levels. She cites many examples of residents who were thought to have difficulty in expressing themselves showing unexpected and very rewarding responses. (Kitwood 1995) also cites anecdotal evidence for improvement in well-being over time in people with dementia staying in places where an emphasis on positive person work is made. Similarly, (Bell & McGregor 1991) report evidence of improvement in people with dementia following admission to Spring Mount nursing home. However, it could be argued that the anecdotal evidence cited is chosen to illustrate the very point the researchers were hoping it would. In other words the researchers may either be seeing what they want to see or not reporting the cases where negative results have occurred. It could be that a positive reaction from a resident is remembered in amongst many inappropriate ones. So if research in this area is to gain credibility it needs to adopt a less anecdotal approach. (Sixsmith, Stilwell, & Copeland 1993) aimed to provide more systematic, empirical data for this very purpose. Their study looked at people with dementia who were thought to have particular problems who, when moved to the experimental homes, showed a measurable improvement in cognitive function - sometimes called 'rementing'. Although it could also be argued that perhaps these people may have also been depressed, and hence had reduced cognitive function as a result, which lifted when more attention was paid to them it nevertheless still shows the more positive outcome of good quality care.

Summary so far

This review has shown the problems with adopting a purely bio-medical approach in isolation. It has highlighted the pitfalls of a dialectic approach but also its benefits, particularly for care of the patient. However, despite the reports, albeit many anecdotal, of improvements in well-being for the person with dementia following improved care, this extra care must necessarily take extra time. In terms of formal care facilities to provide real quality care the staff:patient ratio would need to be increased and hence this approach has financial implications. Additionally, the staff would require extra training - again with financial implications. However, these are not the only considerations; (Lyman 1989b) discusses the problem of staff stress affecting quality of care for patients. The literature on carer burden and stress is already well established (e.g. (Duijnstee 1992). For full time carers in their own homes the extra time and effort required for 'positive person work' may put additional stress on them. In addition, it may be that a less than happy pre-morbid relationship between carer and patient would lead to particular difficulties, for example (Hamel et al. 1990). In contrast (Kitwood 1993) suggests that this positive approach to care actually makes it less exhausting and at times 'stimulating and refreshing'. Indeed (Cohen et al. 1994) suggest that more research should concentrate on the positive aspects of caregiving and how these influence outcome. However it is not clear if Kitwood is referring solely to care within a residential home setting in this instance. Indeed most of the research so far considering care in dementia concentrates on formal care.

Gaps in the psychosocial literature

In designing this project one of the key aims was to look at people with dementia living in their own homes. It has been estimated that more than half of all people with dementia live in their own homes (Gordon, Carter, & Scott 1997), some citing figures as high as five out of six (Gilhooly 1984), yet most of the research to date on psychosocial aspects of dementia have been concentrated in formal care situations. The first section considers this aspect. Secondly, in looking at psychosocial aspects of dementia care we have seen a link between the style of care, positive or negative interactions, and the person with dementia's well-being. But what might affect the carer's style? This thesis focuses on the carer's perception of what it may be like to have dementia and it is to that issue that the final part of this chapter turns.

Dementia in the community

One of the gaps in the literature on person centred care is the consideration of dementia in the community. The majority of studies using this perspective are based within formal care settings, for example (Brane et al. 1989), (Bredin, Kitwood, & Wattis 1995), (Bell & McGregor 1991) and (Bowie & Mountain 1993). The reason for confining study to that of formal care settings may be manifold: Formal care settings offer a captive participant pool. Ethically, observing behaviour in this setting is more easily justified. This is a new area and research on the foundations had to be carried out in this safer field. However, it is now time to move on. Kitwood himself notes the need for work in the community field (Kitwood & Bredin 1992b).

(Briggs et al. 1998) began work to plug this literature gap. They used observation in the homes of people with dementia and their relatives to try to uncover, in some detail, the process of care within this setting. The observations were conducted for part of a day with participants told that the observation time would consist of:

> *'a few periods of time just being with you – much as a friendly acquaintance might do – not getting in your way but just to feel part of the household for a little while and to learn at first hand more about how you manage'.*
>
> (Briggs, Askham, Norman, & Redfern 1998)

The average period of time spent observing the participants was 9.05 hours. However, this was carried out over many visits with most lasting only 2-3 hours at a time. Whilst obtaining some useful material this does not yield a picture of day-to-day life. For example, in my MSc research, which involved making many visits to people with dementia and their relative's homes I found that on leaving the carer would accompany me to the door and, in the absence of their relative with dementia would exclaim, *'they're not usually like this!'* (Carr 1999). Just as you or I can put on an act for short periods of time, e.g. during a job interview or meeting someone new, so can a person with dementia.

"Coming up to me the hostess says: 'Isn't Iris wonderful?' *She sounds surprised, perhaps thankful that there is no squeaking or gibbering going on. I am conscious of a base sense of annoyance, even exasperation. People who see Iris on such occasions assume there must be nothing much to worry about. Suppose I were to say to our hostess, 'You should see how things are at home'. Thank goodness one cannot or does not say things like that at parties."*
(Bayley 1998)

Or as Judy Seegmiller, who cared for her husband, Al, neatly puts it:

"No one really understands until they spend extended periods of time with the person including the nights".
(Seegmiller 2000)

What was needed was more lengthy stays. Breaking ground on research with people with dementia, this study uses participant observation as a main research methodology for exploring their day-to-day lives. Staying with the participants for up to three days at a time I was able to witness, first hand, some of the problems and some of the good times previously uncaptured by research.

The carer's perception of dementia

Social death – an introduction

This research addresses the factors which may be at play in making carers treat the person with dementia in ways which are damaging to their personhood. One possible aspect may be the carer's own view of what it may be like to have dementia. If they feel that their relative is 'already dead' they may behave differently towards them, perhaps in a way which diminishes their personhood. This idea of social death has been investigated by (Sweeting & Gilhooly 1997) who found that a third of their sample of 100 carers believed that their relative with dementia was to some degree socially dead. However, they also found that this belief was rarely transferred into behaviour. They note that social death has not been measured before and hence used observation and interview techniques to try and elicit it in their study. This study seeks to investigate social death using a variety of measures detailed in chapter five.

What is social death?

Biological/physiological death, the end of cellular functioning within a person, becoming clinical death on medical examination, is marked in Western societies by rituals such as the funeral and religious ceremony. Social death, the end of a person's life as viewed by others usually co-occurs. However, social death may happen at a different time. For some the loss of a loved one can trigger coping strategies which may include acting 'as if' the person were not dead. For example setting an extra place at mealtimes, talking to the person etc. In this scenario it could be argued that the person is not socially dead. However, another possibility is that the person will suffer social death before biological death. In other words be 'written off' as a person before cellular activity ceases.

(Sweeting & Gilhooly 1992) identifying three groups of people who they felt were more likely to be at risk from social death, noting that these three groups may coexist in the case of dementia, thus increasing their vulnerability to social death.

1 Those suffering from a lengthy terminal illness
One example may be terminal cancer, where the relatives are expecting the death of their loved one and this may lead to social death of the person before biological death.

2 The very old
Societal norms for age of death may lead to social death in those who have outlived the expected time.

3 People with loss of personhood
This section of people may include the demented and comatose.

Background to research on social death

The first mention of social death in research was by (Glaser & Strauss 1965) looking at 'non-person' treatment of patients and also 'senile patients' who were placed in institutions by their families and never visited again, as if they no longer existed. However it was not a new phenomenon. (Sweeting 1991) charts the course of its arrival on the academic plane citing (Lindemann 1944) work on anticipatory grief in relatives of servicemen in WWII. He found that the relatives had 'written off' their loved ones once they left for war and that this made their homecoming difficult. Goffman (1961), although not using the term anticipatory death or social death, referred to 'mortification of the self' with respect to people in total institutions and later to 'non-person treatment' of patients in mental institutions (Goffman 1963). His works highlight the effect of being treated as if dead on the person's self, eroding the person's selfhood, and this links strongly to the work of (Kitwood 1990) on malignant social psychology. (Sweeting 1991) differentiates between social death and anticipatory grief suggesting that one can lead to the other and vice versa.

Evidence for the existence of social death in dementia

Many elements of malignant social psychology would suggest that the person with dementia was being treated as a non-person, for example objectification, stigmatisation, ignoring. Some of my observations of such were made during interviews with carers in a previous study (Carr 1999). Elaine (a carer) looks after her mother, who has dementia, at home. *'My Mum's already dead'* she told me.

In a dementia care home, in the presence of her mother-in-law who has dementia, Sheila said *'she used to be compos mentis'.*

The manager of a dementia care home showed me proudly round the home. In full earshot of all residents in the lounge she pointed at some of the ladies sitting in chairs announcing *'she's a stage three, she's a stage three – not much you can do for them'.*

Shirley Nurock, a carer, described herself as *'being a widow with a husband', (Nurock 2000).*

Additionally this has been reported in the literature, for example, (Cohen 1991) reports carers describing the long process of watching a loved one die from dementia as a *'living funeral'.* (Jones & Martinson 1992) suggest that carers experience a two stage bereavement, one during caregiving and the other following their relative's death. One of their carer's describes her experience of caring as *'a ten year funeral'.* This notion is reiterated by (Jenkins & Price 1996) who suggest that *'...relatives may grieve for the person they knew, long before the physical demise of a loved one'.*

This feeling of a person with dementia 'no longer here' is again summed up by (Miesen 1992): *'As the disease progresses the patient may no longer recognise the spouse (or other family members). In a sense, the spouse has already lost his or her partner even though he/she is still living'.*

Even Bob Woods' book, written for carers, is entitled *'AD – coping with a living death'.* (Woods 1989).

Some have made suggestions as to why this may occur, for example (Lewis 1998) suggests that to preserve good memories of the person with dementia their spouse may draw a distinction between the person before and after the onset of disease. This may take the form of seeing them as an *'empty shell'*, *'not the person I married'* or even '*dead'*. (Golander & Raz 1996) suggest that non-demented '*normal'* people view having dementia as making life simpler, *'releasing one from the burden of the past, and the premonitions of the future'.* The authors suggest that family members seem to view dementia in terms of *'the merits of confusion'* and give the example *'mother is better off this way, at least she does not know what is happening to her'.* Here it must be argued that their mother may be very confused and does not know what is going on. However from the viewpoint of person centred care it could also be argued that even if she is very confused she may probably be frightened by this uncertain world and hence benefit from reassurance from carers.

On the other side of the coin, not accepting social death but framing dementia in terms of, for example, *'just a bit of a memory problem'* do not assume that their relative is socially dead. This belief may be then reflected in their caring style which would in turn help to retain the personhood of their relative. Of course the degree or severity of dementia may also play a part. It is possible that social death could occur when, for example, the person with dementia no longer appears to recognise their carers or when they can no longer communicate their needs. This again highlights the need for longitudinal studies so as to view any changes over time.

Social death and the enormous task of caring

Caring for someone with dementia is no easy task. Having carried out my observations and shared the homes of couples facing this problem I am aware of the immense difficulties and heartache. I had no idea of the extent of these before my studies. Social death may be one way of coping with a situation which none of us would relish. Indeed (Lewis 1998) felt that some carers used social death as a way of preserving good memories of happier times. (Kitwood 1997) suggests that social death may be the result of carers being influenced by the dominant medical ideology surrounding dementia which again highlights the need for a change in direction in our approach as researchers. So, whilst taking care not to belittle the task facing carers, it is to the attention of the person with dementia that this study turns and seeks to help with the hope that this approach could in turn help their carers too.

Social death and personhood

The concept of social death may link closely with the loss of personhood. Can a person who is no longer treated as if they are socially alive still retain personhood? And conversely, can a person who no longer shows signs of retaining their personhood be treated as if they are socially alive? (Sweeting & Gilhooly 1992) include loss of personhood as one of the characteristics which may lead to social death, alongside 'lengthy fatal illness' and 'very old people'. People with dementia may fit into at least one of these categories thus increasing their chances of social death. The two questions posed at the beginning of the paragraph are answered by (Sweeting & Gilhooly 1997) who cite the care that some relatives show towards someone in a vegetative state as an example of loss of personhood not automatically leading to social death. The converse, social death then leading to loss of personhood, is the essence of

Kitwood's claims for negative interactions from some forms of malignant social psychology.

Research on social death in dementia

Research in this interesting and potentially useful field has only recently emerged with (Sweeting & Gilhooly 1997) carrying out an exploratory study to find the extent of social death in people with dementia. Their sample of almost 100 couples (people with dementia and their carers living in their own homes) underwent a semi-structured interview aimed at measuring social death. As there were no existing questionnaires to measure social death they devised their own questions. These questions considered various aspects of the person with dementia's life from the perception of their carer.
For example:

Does (sufferer) seem to know and understand all that's going on?

Does (sufferer) ever talk about what's happening?

The authors hoped that these questions would tap into the carer's view of how aware their relative was about their condition.

Further questioning looks at whether the carer believes their relative should be treated with dignity – i.e. as a person, whether they ever think about their relative's death (anticipatory grief), finally whether the carer felt their relative's life lacked value and that they were 'in some ways already dead'.

Would you agree that in some ways it is as if (sufferer) is already dead?

One problem with this final question, which is actually asking about social death, is that it is presented in a way that the respondent would have to disagree quite strongly in order to refute this.

These questions aimed to measure belief. They then used observations to look at behaviour. These observations were reporting on whether the carer treated their relative as if they were socially dead, considering only their physical needs and ignoring their social ones ‘as if’ they were already dead. These observations are in line with the ideas of maintenance of personhood.

However, considering the limited time or opportunity they had to observe the carer interacting with their relative with dementia they had to infer behaviour from the interview transcripts, to see if beliefs and behaviour matched, acknowledging the limitations in this method.

They conclude that a third of their 100 carer sample believed that their relative with dementia was to some degree socially dead and behaved ‘as if’ this were the case. However, they also found that a further third of their sample showed incongruency between belief and behaviour. They suggest that this may be because relatives are acting as if their relative does know what is going on ‘just in case’ they really do. A final third of their participants did not believe or behave as if their relative was socially dead. They conclude that their results suggest a ‘Guttman’ type scaling for the dimension of social death. In other words behaviour and belief were congruent for two thirds of their participants at the extreme ends of the dimension. The middle third showed incongruity: either they believed their relative to be socially dead but behaved otherwise, or they behaved as if their relative was socially dead but believed otherwise. The latter group consisted of very few people, the former being the much more usual presentation.

So it appears that at extreme ends of the social death spectrum belief is translated into actions or style of care. In other words the carers who did not believe that their relative was socially dead acted in ways which parallel Kitwood’s positive person work preserving their relative’s personhood. Conversely, carers believing that their relative was socially dead treated them in manners which parallel Kitwood’s malignant social psychology thus diminishing their personhood. It is possible that this process may be cyclical and self-fulfilling setting up a continuous spiral of conditions. It is the incongruent third who do not fit this model and there may be many reasons for this.

Social death and the current study

This study uses both observation and interview techniques to capture data on social death, both beliefs and behaviours, with the couples. However, a lengthy observation enables behaviour to be witnessed in different contexts and over time. Similarly, verbally reported data are not just taken from one interview but is collected across the visits. Observations are based around Kitwood's malignant social psychology and positive person work. For example, the observer can obtain tiny clues about the presence of social death by noting how the carer refers to their relative – do they use the past tense? (Kirsi, Hervonen, & Jylha 2000) noted that on interviewing carers some of them talk about their relatives in the past tense even though they are still alive. This would indicate a belief of social death.

The interview (detailed in chapter five) encourages the carer to provide examples where possible so as to help gather data on both beliefs and behaviour.

Conception of the methodology for measuring social death

As (Sweeting & Gilhooly 1997) note, there are no existing measures for social death. The process of deciding how to measure social death was not an easy one and is detailed fully in chapter five. Initially a diary method for capturing information on social death was trialled. However this was not found to be an ideal method being both time consuming for the carer and not always collecting the data of choice. Hence a different method was sought. It was decided to make use of the growing number of biographies written by carers of people with dementia and to analyse these for aspects implicated in social death. Six biographies were subjected to in depth thematic analysis and key areas for exploration via interview were elicited. The final step involved constructing an interview schedule to be used with the carers. These stages are detailed in chapter five and the results in chapter six.

Chapter three

Methodology:
Case study

Introduction

(Bromley 1986) describes a case study as 'the bedrock of scientific investigation'. Given this definition we might wonder why the case study has not been used more extensively in the field of psychology. (McAdams D P 1997) points to a division between psychologists who advocate using the case study as a method of enquiry and those who don't. He suggests that *'It is ironic that the field defined as the scientific study of the individual person should harbour deep ambivalence about the very business of examining cases of individual persons' lives'.* This division, as with many similar debates in psychology, leaves one group on the defensive, battling against the prevailing, dominant view of the current time. Today we find that those on the defensive are users of the case study approach. However, there is also a growing body of support for this type of enquiry which is capturing the interest of psychologists in both the UK and USA (Fishman 1999). This chapter aims to explore the case study method, setting it in its historical context, examining the critique to explore why it may be an under-utilised approach, and following through to the present day debate which hopes to change that. In looking at the critique a range of examples will be presented to illustrate the variety of areas within psychology which have used this method to varying levels of effectiveness. Finally the focus is narrowed to consider why the case study approach is suitable for studying people with dementia and some current examples are cited and explored.

Definition

The term case study has a different meaning within different disciplines. For example, within the area of business studies it could be the study of a particular event or company, whereas in psychiatry a case study is taken to mean the clinical account of an individual with a mental health problem. Within psychology a case study may be defined as *'an account of a person in a situation'* (Bromley 1986). This account is usually of a particular period in the person's life which is marked or dominated in some way by a critical event, such as an illness, loss of a job, or lottery win, for example. This period in the person's life would be one of the key events selected in telling the story of their life. Since the case study considers a segment of a person's life, usually the current situation, it is differentiated from the life-history approach which looks in a less-detailed way at all of the key events in a person's life. Similarly it is also different from a psychobiography which looks at a person's whole life from a psychological perspective, although this may be carried out using a case study methodology.

Historical background

Historically the case study as a method of enquiry can be traced far back in history to the analysis of military reports, with a more recent history in judicial investigations (Bromley 1986). In psychology the case study became popular during the early part of the twentieth century, alongside the emergence of psychoanalysis as one of the main schools of thought. Here the case studies were modelled on the method of medical enquiry. The end of world war two saw an increase in popularity of what were considered to be more objective methods of research such as the experiment, the questionnaire and also psychometric measures. The case study method was relegated to a second division to be used on occasions by personality and clinical psychologists. However, in the 1960s it took on a renewed level of interest, helped by the humanistic movement and their focus on the uniqueness of individuals which was gaining support at this time.

Uses of case studies

(McAdams & West 1997) suggest that case studies have three functions: Firstly to illustrate predetermined concepts or theory. For example, Freud, in reporting his case of Dora (cited in McAdams and West 1997) uses her case to help explain certain aspects of the psychodynamic approach; Secondly, case studies can be used to explore an area by induction. For example, (Irby 1992) used a case study approach to generate a model of decision making used by physicians when instructing medical students on their ward rounds. Finally, case studies may be used to make a variety of comparisons. A case study can be compared with a theory to evaluate how the theory helps to illuminate a certain aspect of a particular individual's life. Multiple case studies may be compared to explore aspects of theory which may have greater explanatory power in some individuals than others, this helping to continually develop theory. Additionally, different theories may be evaluated by comparison using case studies. By considering a real life situation each theory can be compared in order to evaluate which sheds more light on the individual. For example, (Coleman, Ivani-Chalian, & Robinson 1999) use this approach to compare two theories of self in later life.

A further use, perhaps not explicitly addressed by the McAdams and West's (1997) list is that of problem solving. (Fishman 1999) favours the use of the case study in this way, entitling it a 'pragmatic' case study. For example, (Woods 1999) reviews case studies of behavioural therapy interventions with people with dementia aimed at increasing their well-being. He contrasts this single case approach with the randomised controlled trials used within pharmaceutical trials, emphasising the importance of case based studies where exploration of a problem is the goal. This comparison can perhaps also be used to suggest the complementarity of both single case and randomised controlled trials in working towards the same overall aim of improving the quality of life of people with dementia.

(Stake 2000) prefers to view the uses of case studies more simplistically, dividing them into intrinsic and instrumental. An intrinsic case study is one investigated just for its own sake or interest, whereas an instrumental case study provides an insight into an issue or theory. Instrumental case studies, according to Stake, may be joined together to form collective case studies.

Critique of case study methodology

Despite these wide ranging uses applicable to many fields of psychology, the case study is still viewed by many with scepticism. For some, the words case study are synonymous with qualitative and hence the qualitative versus quantitative debate is engaged (Hammersley 1992). However, this is based on a misunderstanding of the nature of a case study. Within the umbrella term 'case study' a variety of data collection methods may be used, both qualitative and quantitative, hence the case study may be more appropriately viewed as a research strategy than a single method. This strategy can be used by researchers coming from different epistemological positions. (Fishman 1999) clarifies this issue by suggesting that the literature on case studies can be divided into three groups; case studies located within the positivist paradigm, the hermeneutic paradigm or those located under the pragmatic heading. According to Fishman, the pragmatic approach represents a middle way, a solution to the on-going debate of the relative merits located in the positivist versus hermeneutic paradigm.

Alongside the qualitative versus quantitative deliberation runs the nomothetic versus idiographic debate. (Runyan 1990) locates the under-use of the case study within this debate, suggesting that it may be due to *'changing intellectual fashions about what it means to be 'scientific''*. Runyan takes the view that to say science is about the study of general laws as opposed to the particular would be to say that the study of astronomy and biology, for example, is not a science. However, a far cry from Bromley's (1986) description as *'the bedrock of scientific investigation'*, the case study method is often viewed as a less rigorous method of enquiry than its alternatives. Bromley (1986) addresses this problem by purporting the use of what he terms the quasi-judicial method. This method, based on an analogy with the process of law, requires that the most relevant interpretation from the case study data are reached by a continuous process of critical examination of available evidence. Hypotheses are formed and tested against further incoming data and either confirmed or rejected and reformed. This systematic method brings the rigour of a scientific study into the analysis and understanding of an individual's life. Evidence may be obtained via qualitative or quantitative methods, and the greater the variety of data sources the more evidence available for scrutiny and comparison. This triangulation of data forms an important aspect of a rigorous case study also advocated by (Runyan 1981;Runyan 1988), who states that producing a convincing interpretation of events which stands up to rigorous cross-examination requires drawing on multiple data sources available and then producing an interpretation which is consistent with this amassed evidence. He cites the cases of Van Gogh and the many alternative explanations as to why he cut his ear off and King George III and the many explanations for his puzzling illness as examples of this process. However, use of multiple data sources and methods within the case study which help to provide a more rigorous approach have not always been adhered to by researchers labelling their methodology as following a case study strategy. For example, (Owen 1998) in looking at the effect on self-concept of the diagnosis of HIV of a gay man cites (Bromley 1986) in her methodology section, yet uses only one single interview for data collection, and makes no attempt to corroborate any of her findings with other people known to the man or by using different measures. Similarly, (Scanlon & Weir 1997) in their research with mental health nurses cite Bromley's (1986) ideas

about building up cases to produce case law, but use only single interviews with 10 individuals in their 'case studies'. Further, they perform a thematic analysis of the data across the 10 participant's data rather than presenting them as cases. It would appear that they have cited Bromley to justify using individuals and then generalising from them without fully understanding the context in which Bromley felt this to be possible - that of rigorous case studies. It is possible that studies such as (Owen 1998) and Scanlon and Weir (1997) lend support to the argument of a case study as non-scientific. However, other studies have applied a more rigorous approach in producing their case study reports. (Sapru 1998) uses a series of interviews to look at the development of identity in seven Indian psychology students, using (Erikson 1963) developmental theory as a framework. This enabled the checking and reforming of ideas and hypotheses throughout the series of interviews as advocated by Bromley, but the study might have benefited from more diverse data collection methods for corroboration by triangulation, such as the use of self-report questionnaires or diaries. (Balk & Vesta 1998), on the other hand, in their longitudinal study of a bereaved student used both standardised self-report questionnaires and an extensive diary as data sources. Similarly, (Dale 1995) in her research on nurses' perceptions of patients quality of life used interviews and documents for method triangulation. In assessing a case study (Bromley 1990) suggests that *'the degree of confidence attached to the findings of a case study depends on the amount and quality of the evidence and on the cogency of the arguments used to make sense of the evidence'.*

Bromley's style of writing, with its philosophical inclination, has perhaps not helped make his ideas accessible (Emson 1987). His critics also question his analogy with law; for example (Emson 1987) points out that 'hearsay', which is generally inadmissible in court, is useful to the case study researcher in data collection. Views of friends or relatives on the periphery of the central character's life are often invaluable in drawing together a complete picture. However, perhaps Emson misses the point that Bromley's quasi-judicial process would not accept unsubstantiated 'hearsay' either. (Shapiro 1986) accepts the analogy as a useful one by qualifying that the term 'quasi' in quasi-judicial case studies is used because of the differences between a court process and psychological enquiry. However, he criticises Bromley's lack of empirical examples of the effective application of the method.

Returning to the critique of the case study, the natural progression of the nomothetic versus idiographic, the general versus the particular, argument is to suggest that it is difficult to generalise from a single case. Again (Runyan 1997) comes to the defence of the case study by suggesting that an equally valid question is *'How can you particularise from that group or population study?'* Taking the average of a whole population may produce characteristics which do not apply to anyone within that group. Bromley's analogy with judicial process in his quasi-judicial method continues with his description of case law. Here, he suggests, by looking at similar cases in a comparative way, you should be able to produce a conceptual framework from which other similar cases can be studied. (Yin 1992) agrees and adds that studying a small number of cases in depth can provide an explanation of cause and effect relationships in cases of a similar type. (Edwards 1998) sees the importance of drawing knowledge from a range of cases to help understand an area of interest. (Fishman 1999) takes this a stage further and proposes setting up a database of cases which researchers could access thus building up knowledge from the sharing of single case findings. (Bromley 1986) suggests that it is useful to select prototypical cases, which are good examples within the range or limits of the theory or model being examined. For example, (Coleman, Ivani-Chalian, & Robinson 1999) used case studies to examine self-esteem in later life, and chose five cases for their prototypicality in representing different manifestations across time of self-esteem in later life. This bottom-up approach of the case study method, working from individual cases to a set of cases by developing case law is in contrast to the top-down approach of theory to individual rule. However, (Runyan 1997) argues that different levels of analysis can still work with the same overall aim.

Moreover, the work of (Coleman, Ivani-Chalian, & Robinson 1999) in considering real-life cases to evaluate two different theories of self in older age illustrates the usefulness of the case study in bridging the gap between the nomothetic, general theory and the idiographic, individual life.

The case study approach and dementia research

Recent research in the field of dementia, as detailed in chapter two, suggests that the current medical model of cause and treatment is not adequate to explain all the findings. A growing body of researchers are now considering the importance of psychosocial factors in both the progression of the disease and the associated care of the individual. The complex interplay of biology and psychology in this field has not been fully understood. Hence a very appropriate method for exploration of all possible contributing factors in the outcome of an individual with dementia would be the case study. (Woods 1999) advocates the use of *'carefully controlled single case studies'* in this area. Using (McAdams & West 1997) classification of uses, the case study in this relatively new area of research would be used to both develop and evaluate theory.

Research on dementia using the case study approach to date has begun to uncover some interesting findings. In particular, research has concentrated on the role of social interaction and the role of others in the outcome of the person with dementia. As (Sabat 1994) points out, although there is no cure for dementia, if we discover that social aspects are important factors in well-being then some change in the form of an intervention could be made to give people with dementia a better quality of life. This takes the form of a two-pronged attack; firstly in the development and evaluation of theory, and secondly in the development of an intervention or therapy. (Mills & Coleman 1994) used this approach in their case study research looking at emotional memories in dementia. Taking the link between emotion and well-being their research highlighted the importance of others in helping the person with dementia to retain memories and hence keep a sense of self intact. (Sabat et al. 1999) supports the importance of others in maintaining aspects of self for people with dementia. He sees the nature of this interaction as crucial - the other must be a *'patient listener'* who is prepared to help with a joint construction of self. For example, his case study of a man with dementia, Dr B, details how his sense of self as an academic was maintained by his involvement in the research, *'the project'* as Dr B named it. Staff at the day centre took time to help re-construct this sense of self by putting the dates of his meetings with the researchers on the main notice board, at Dr B's request, which would be seen by both staff and other patients.

But interactions between the person with dementia and their carers do not always take on this positive character. Case studies investigating the very nature of the relationship and interactions help to tease out the key factors at work here. For example, (Vernooij-Dassen et al. 1998) studied the interaction process between carer and person with dementia by using interviews and a diary written over a period of two years by the carer, in their case study of 'Alice'. (Sabat 1994) looked at the relative difference in well-being of a person with dementia in two locations; home and at a day care centre, and related these differences to different styles of interaction using (Kitwood 1990) malignant social psychology. These four examples of the use of case studies in dementia research illustrate the importance of the case study as a tool in psychological research. Each has made a contribution to the understanding of psychosocial aspects of dementia, thus furthering theory and the development of possible interventions.

Case study examination used in the current study

Five case studies are presented in this thesis. Each represents the results of a large number of contact hours with the participants during a two and a half year research period. By employing a long research period the case studies have an important longitudinal element. In looking at psychosocial aspects of dementia the important factors influencing well/ill-being may be many and varied. Hence a method which allows for a full examination of the life of the person with dementia is demanded. For example, (Adams 1998) stresses the importance of looking at the whole family rather than just the primary carer. A case study approach fits such criteria.

The current study investigates the link between psychosocial factors, such as style of care interactions, and the person with dementia's well/ill-being. Critics of the qualitative method of inquiry could argue the limitations of such a small sample number. However using a case study approach allows for more thorough investigation:

'The intensive study of a small number of cases can provide an explanation of cause-effect relationships within or between families of a similar type'. (Yin 1992).

This piece of research attempts to employ a rigorous approach to the compilation of case studies as advocated by (Bromley 1986) and (Runyan 1981;Runyan 1988). In order to build up evidence which can be used to compare and corroborate a variety of data sources have been employed and are detailed in the following sections.

Participant observation

Each family taking part in the study agreed to the author spending time with them in their own home in order to see *'warts and all'* (Pointon 2000). This entailed a number of visits over the two and a half year period of study, of up to three days, including overnight. During each stay the author utilised a variety of methods for looking at the person with dementia and their carer's situation. In addition, where possible the author also carried out participant observation with the person with dementia in day care centres. This was a vital source of information as it enabled comparison between behaviour at home and outside the home when interacting with different people.

Since participant observation formed the main strategy for data collection it has been awarded a chapter in its own right. This chapter details the exact nature of the observation, the ethics of such an investigation and, of course, the benefits and limitations of such study. Below are detailed the individual areas of data collected during these periods of observation.

The person with dementia's well / ill-being

This was investigated by a variety of means to provide a number of different sources of evidence. Firstly the person's well and ill being was assessed by using well and ill-being profiles which were devised by the (Bradford Dementia Group 1997a) building on the 12 indicators of relative well-being cited by (Kitwood & Bredin 1992). This method also allows changes in patterns of well/ill-being to be monitored across time and hence was ideal for use in a longitudinal case study.

These indicators require the observation of non-verbal behaviour in particular as this often reveals the underlying emotion not always conveyed verbally. In addition for many people with dementia non-verbal messages may be their main channel for communication when speech becomes limited. Indeed (Kitwood 1993) suggests that dementia sufferers have a heightened awareness of body language.

Dementia Care Mapping (DCM)

What is DCM?

DCM is an observational tool used to evaluate dementia care from the person with dementia's perspective. The idea for DCM was conceived when in 1989 Tom Kitwood and his colleague Kathy Bredin were evaluating one of the Bradford day centres specialising in dementia care. Although they were able to elicit the views of carers at the centre using questionnaires they became aware that there was no method to obtain the views of the very people this centre was designed to serve – the people with dementia. In addition, whilst some of the day care users may be able to present their views verbally, this method would exclude those with verbal impairment. As a result they designed an observational method which looked at well/ill-being and accompanying activity. This tool was based around the assumptions underpinning the person centred approach to dementia care. The importance of interactions with others that either help to maintain or to undermine personhood form a central position. When looking at a number of people with dementia in a care setting the assumption that their relative well-being equates to good quality care is made, since the day to day changes in people's moods will be averaged out.

Now in its seventh edition (Bradford Dementia Group 1997b), DCM has evolved and developed via input from the observers or 'mappers'. Originally designed to be used exclusively in formal care settings the eighth edition, which is currently under development, is considering its potential for use in other settings. However, to date there is no literature trailing its use in informal care settings. One aim of this thesis is to explore this possibility.

How does DCM work?

DCM involves observing a person with dementia in their formal care setting (excluding the bedroom, bathroom or any other 'private' areas) and at the end of every five minute period noting:

1 A behavioural category code (BCC), in the form of one of the letters of the alphabet, which represents the activity the person has been involved in and

2 A number from –5, -3, -1 to +1, +3, +5 that best represents their level of well/ill-being (WIB score) during this period.

These codes are presented in appendix one.

For example, a person who has been showing moderate signs of unattended distress such as crying or anxiety would be given the code D, -3.

A person eagerly joining in with a sing-a-long, clearly showing strong emotion would be given the code E, +5.

Alongside the coding are a number of rules to help the mapper decide which code to use in certain situations.

Degeneration

This rule is based around the idea that good person-centred care involves contact or interaction with others. Hence if the person with dementia has been in a state of ill-being (a negative WIB score) for 30 minutes without any contact from others the WIB score drops a level, even if the accompanying activity remains the same. This applies to the following categories:

C	being socially uninvolved, withdrawn
D	unattended distress
K	independent walking, standing, or moving in a wheelchair
L	participating in work or work-like activity
U	communicating without receiving a response
W	repetitive self-stimulation
Y	talking to oneself or to an imagined companion

The combination rule allows for the situation where any combination of the above categories are recorded in series. In this situation degradation also occurs.

Appropriate sleep

Periods of sleep during the day may be beneficial for many older people. However if a large proportion of the day is spent sleeping this may be due to lack of stimulation or perhaps medication. The person-centred approach would suggest that oversleeping should be investigated and hence after an 'appropriate' amount of sleep has been observed the mapper should degrade the WIB score accordingly. Appropriate sleep is defined as one hour in day care settings and one and a half hours in residential settings. For this research the period of one and a half hours was defined as appropriate sleep as residential settings are most like the informal care setting situation.

Types of category

The order of precedence when assigning behaviour category codes is:

1. Type one categories – A E F G H I J L M O P R S T X
2. K
3. Type two categories – B C D U W Y
4. N

Type one categories are activities which are felt to be very useful in maintaining well-being as they involve active interactions. Type two categories do not have this positive aspect.

In addition to these codes the mapper also notes any instances of malignant social psychology during the mapping period. These are referred to as personal detraction codings within DCM. Alongside these any instances of good care practice are recorded in the same way as positive events.

The results of mapping have manifold uses. As well as being able to see what kind of interactions may help to raise a particular individual's level of well-being, the mapper can also identify activities which are not present (usually type one activities) and use these to suggest interventions which may raise levels of well-being.

The decision to use DCM

During the pilot study, detailed in chapter four, I spent a whole day with participants in order to assess the strengths and limitations of participant observation in these settings. I had already been on a basic DCM training course and hence was familiar with its coding system. Having learnt and used the codes in formal care settings to good effect I could not 'un-learn' these ways of thinking. During the days spent with the participants on this pilot study I found myself thinking of these codes whilst I observed the family. When I made field notes I would often use the codes to describe what was happening and the level of well/ill-being. In particular if large periods of time were spent 'just sitting', I felt that mapping could be one way of representing this to the outside world. Hence I made the decision to try and use aspects of the DCM system within the main study. I found that under certain conditions I could retain codes for mapping for approximately 45 minutes at a time before retreating to note these down. This meant that I could map without constantly taking notes, which I had already decided would be counterproductive.

Although the original version of DCM had not been designed to be used in informal care settings or with only one person at a time it was felt that this could still provide useful information. The averaging out of day to day moods between individuals when using DCM for a number of people in the same care setting would not be possible. Hence mapping of an individual would also have to be seen in context. Since this method of data collection would be taken alongside other observations – in other words this would not be the sole form of data – it was felt that some of these difficulties would be overcome.

Evaluation of DCM as a method

One of the criticisms of any observational method designed to be carried out ‘in the field’ is that the very presence of an observer can change the very behaviour you are hoping to observe. (Kitwood & Bredin 1992) accept these ‘Hawthorne effects’ as a potential problem area for DCM but counter this with the fact that most mapping will be of approximately six hours in duration, during which time the observees will become desensitised to the process. In addition they note that care staff are more likely to exaggerate the underlying usual patterns of behaviour, in other words their current style of care will still show through.

(Edwards & Fox 2001) suggest that as mapping is usually carried out during the day this excludes care carried out during early mornings, evenings or at night. They argue that quality of care cannot be generalised from observations made during the day alone. However, it could be counter argued that any episodes of poor quality care during the day are important and that it may be difficult to imagine that poor quality care during the day will not be paralleled by poor quality care at night. In their original paper (Kitwood & Bredin 1992) highlight the potential problem of not mapping in personal areas. However, in line with the above argument they note that staff who are attending to public needs are also likely to be those attending to private ones.

In contrast there have been a number of studies citing the positive aspects of DCM as a tool in formal dementia care settings. In the UK, (Brooker et al. 1998) and (Barnett 1995), and further afield in Denmark, (Nielsen 2002) and Finland, (Sormunen, Topo, & Eloniemi-Sulkava 2002).

(Jarrott, Fruhauf, & Nester 2002) suggest that they are the first study to investigate the validity of DCM. In looking at a day care centre they used the Apparent Affect Rating Scale, interviews and an activity checklist to compare with DCM observations. They found a significant association between DCM assessment of affect and activity and the other measures used.

Politeness strategies

(Temple, Sabat, & Kroger 1999) suggest that if a person with dementia uses what they term 'politeness strategies' then this indicates an awareness of other people's feelings. They state that people with dementia are often thought to be lacking in social skills as well as having cognitive deficits. Hence if the person with dementia is found to be using politeness strategies then this 'may suggest a level of competence not generally assumed to exist in these individuals'. For example, a person with dementia in conversation with Sabat interrupts his talk, but shows politeness to compensate for the interruption. In other words, he shows signs of understanding what his interruption made Sabat feel like. In another example a person with dementia showed different styles of speech to address another resident and the interviewer, showing some level of awareness. Finally, a woman with limited speech chose to add the word 'please' after a request, which could have been more easily worded without. Hence it was decided to include observations of 'politeness strategies' as this may help to indicate the person with dementia's awareness of others.

Aspects of selfhood

(Sabat, Fath, Moghaddam, & Harré 1999) consider various facets of the self, as detailed in chapter two:

Self one – which is our own perception of our continuing experience as a unitary item.

Self two – which is the mental and physical attributes we have, or have had, throughout our lives for example, being Japanese or a teacher.

Self three – which describes the various ways we present ourselves to the world and which requires the interaction of others for its joint construction.

This area for investigation was explored during the visits by building on both observational data and verbal reports from relatives, carers and friends where possible.

Carer support for intact abilities

As (Sabat 2001) points out, more prominence should be given to recognising and supporting intact abilities of the person with dementia rather than concentrating purely on deficits as many of the traditional cognitive tests do. By looking for remaining abilities and helping to bring these out the person with dementia's personhood can again be strengthened. However this does require the aid of others and hence during the visits observations of this phenomenon were made if present.

Validation of emotion

Validation of emotion is one of the key aspects of good care as set out by (Kitwood 1997). It also forms the basis for validation therapy (Feil 1982). (Sabat 2001) sees validation as occurring when the carer recognises and supports the person with dementia's intact abilities. As an important area for interaction, validation was highlighted as an area to look out for during my observational visits.

The carer's perception of dementia and social death

This aspect was initially measured by using a critical event diary, completed by carers. However, this was not found to be a satisfactory measure and hence an interview schedule for use with carers was designed. This is detailed in chapter five.

Other measures

The Behaviour Rating Scale for Psychological and Social Problems (BPS, (van Loveren-Huyben, van der Bom, & Bronts 1988), appendix two)

The BPS is a rating scale developed in the Netherlands to assess psychosocial problems amongst the elderly and used for the first time in the UK in Southampton by (Meade 1993). This 35-item scale is designed to be completed by the carer and gives an indication of the person with dementia's degree of impairment in the domains of cognition, mood and social contact. After each visit the carer was asked to complete this scale and results were compared with the same scale as completed by myself. This allowed for (i) a comparison of my views with those of the carer and (ii) observation of perceived changes over time.

The Bristol Activities of Daily Living Scale (BADLS, (Bucks et al. 1996), appendix three)

The BADLS is a 20-item questionnaire, to be completed by the carer, designed specifically for use with people with dementia. It was developed with substantial input from carers, and is reportedly easy to use and relatively short. This helped to provide detailed information on the practical ability of the person with dementia from the perception of the carer and myself and as with the BPS it was completed after each visit.

Recruitment of participants

Pilot study

Participants for the one day observation pilot study were recruited with the help of Crossroads, a care service. The inclusion criteria were that they had to be looking after a relative with dementia living in their own home. An information leaflet was given to potentially interested families who then contacted me via a reply-paid letter if they wished to consider taking part. Two families came forward and in both cases I visited them to discuss what the day would involve and give them the opportunity to have any questions answered. They were asked to sign consent forms and assured that they could change their mind at any time during the observation. Both families were paid £7 for the day by the university in order to cover any additional expenses that my visit might cause.

The main study

Following the pilot study I decided to restrict participants in the main study to married couples and that they should be in a long term marriage. This was to exclude couples who had married later in life and hence did not share early memories, as this was found to be a source of great anxiety for one couple in a previous study (Carr 1999). Spousal relationships were also chosen because this type of caring relationship is less likely to result in the person with dementia being admitted to residential care early on in the disease process (Colerick & George 1986), which meant that the couple were more likely to be living in their own home for the duration of the study. In addition a long-term married couple will have lived together as a dyad for a number of years. Other relationships e.g. mother-daughter are likely to have had a break in living together, perhaps when the daughter has her own family. Additionally, in comparison with a son or daughter as caregiver, a spouse is more likely to provide comprehensive care with less help from either formal or informal support systems (Johnson 1983;Johnson & Catalano 1983). This means that with this type of caring relationship the person with dementia is likely to depend almost entirely on their spouse for care and social interaction. By studying this type of relationship the effects of the marital interactions on patient outcome are therefore not as likely to be 'diluted' by interactions from outside the marriage as with other types of caring relationship.

In addition, the person with dementia had to be at least 65 years of age or older so as to exclude people with early-onset dementia and the carer also had to be 65 or over. By selecting people of this age range it was hoped to find people in a life stage where other priorities, such as employment, do not compete with care-giving. In many cases caring for their spouse at this time in their life may be to some extent 'expected'. Younger caregivers who have competing priorities may have additional problems as a result, for example (Skaff & Pearlin 1992) found younger carers to be more likely to suffer self-loss.

Since the participants were to be found via a day care centre it was assumed that the person with dementia would have mild to moderate dementia and require a fairly high level of care. The person with dementia could either be male or female enabling the dynamics of both types of dyad to be explored during the study.

The participants were found with the invaluable help of a local day care centre for people with dementia. The manageress kindly arranged a 'coffee morning' for the carers fitting the above criteria where they could come along and chat to me with no obligation to take part. This was enormously helpful as I felt the carers were relieved that I didn't fit their stereotype of a psychologist. They were also able to ask questions about how the visits would be arranged and any concerns they had. I was surprised to find that few of them had concerns.

Each couple were paid £10 per day by the university to help cover any additional expenses that my stay would incur.

A representative sample?

In an ideal world a sample representative of the population to be studied should be chosen for a case study approach (Bromley 1986). For example (Coleman, Ivani-Chalian, & Robinson 1999) chose their five cases for their prototypicality in representing different trajectories of self esteem in later life. However, there are a number of problems in the study of people with dementia in terms of sampling. Firstly, in order to obtain a representative sample the whole population of people with dementia living in their own homes with their spousal primary carer should be identified. The main problem here is that families looking after a relative with dementia remain silent. For a variety of reasons they do not become known to the health or social services. For some the family doctor may be the 'end of the medical line' and they may never be referred to a psychogeriatrician. For this reason finding participants from a local day centre was necessarily going to be biased. In addition my sample would obviously only include people willing to let me visit and stay with them in their own homes. (Stake 1995) recognises that *'if we can we need to pick cases which are easy to get to and hospitable to our inquiry'*. This was vital for a study of my intensity and duration.

Initially I had expected people who were doing 'well' with caring for their relative would be those to volunteer. However this was not always found to be the case as will be demonstrated in chapter six. For example, Mr Reed said he wanted me to visit to see *'how difficult it was'*. So although this is a necessarily biased sample it is hoped that the people taking part are representative of some of the wide range of problems and situations facing people with dementia. Some of the couples coped better than others with their experience and hence not just people coping well are presented.

Chapter four

Methodology:
Participant observation

Introduction

Asking questions of people, whether by interview or questionnaire, enables the researcher to capture something of the person's lives within their range of interest. However, to observe a period of that person's day-to-day life allows the researcher a rather different window into their lives. This chapter looks at my decision to use participant observation as the main data collection method by reviewing its use in looking at families. The strengths and limitations are considered and the ethical dilemmas explored. Finally the question of the effect of and on the researcher is discussed by considering reflexivity.

What is participant observation?

Observation in psychology is often the starting point for research. Noticing a behaviour, seeing children play in a particular way, just observing the day to day life around us has often sparked off ideas for research. Sometimes the observation is an unexpected by-product of a different topic of research, for example (Pavlov 1927) in his classic study of conditioned learning was originally looking at the digestive system of dogs when he observed their salivation to the bell.

Observation is a useful method of enquiry for finding out about a whole range of behaviours and reactions and, in particular, for exploring the worlds of those we cannot question in the usual way – for example animals, children and people with communication difficulties.

There are a variety of ways of observing as a research method. One dimension is the structured versus unstructured observation. An unstructured observation would often be used in a new area of research where little was known about the behaviour or reactions that would ensue, whereas a structured observation would take pre-determined categories of behaviour and use these as the basis for data collection.

The observation may be carried out in the laboratory, where tighter control on variables may be taken, for example (Ainsworth et al. 1978) and their ‘strange situation’, which looks at the attachment behaviours of a child towards their mother in a series of pre-determined scenarios in the laboratory. Or the researcher may decide to make the observations in a natural setting ‘in the field’.

Finally the researcher may face the dilemma of their own involvement in the area to be observed. Do they remain on the outside of the group or situation they are observing or do they join in with the situation and immerse themselves as a member? Participant observers see their research role as one of joining the group they are observing. Traditionally a method favoured by anthropologists and sociologists, participant observation dates back to the earlier half of the twentieth century where it was favoured as a method of inquiry by the sociologists of the Chicago School. Whilst observing the researcher partakes in activities to different extents along the continuum:

Complete participation – participant as observer – observer as participant – complete observer. (Junker 1972)

With complete participation the researcher would be working covertly, and observing their participants without their knowledge. For example (Festinger, Riecken, & Schachter 1956) joined an apocalyptic group ‘under cover’. Aside from the obvious ethical problems involved with this they also lent the group more internal credibility as its numbers had suddenly swelled. Similarly (Humphreys 1970) took a covert role in exploring homosexual behaviour in men’s toilets by adopting the role of ‘watch queen’ – a voyeur who would watch out for police to warn the men. (Rosenhan 1973) classic study of mental hospitals used covert methods by having students pretend to hear voices so as to gain admission to a psychiatric ward.

Unfortunately some of these well publicised covert studies serve to give observational researchers a bad name. To try and redress this within psychology the British Psychological Society have a code of conduct under which observation is covered thus:

'Unless those observed give their consent to be observed, observational research is only acceptable in situations where those observed would expect to be observed by strangers'. (The British Psychological Society 1997)

More usually the researcher would operate in an overt manner and obtain the written consent of all concerned prior to observing.

In the 'participant as observer' role the researcher is open about their role within the group but mainly participates. However, this means less time for observation. For example (Whyte 1981) took on this approach and joined the gang in some of their illegal activities. Similarly, (Marsh & Rosser 1978) adopted this role in his study of football hooligans at Oxford United.

In the observer as participant role the researcher joins the group under observation and joins in with activities but is not 'active' in choosing what to do and merely follows what is happening. This allows more time for observation of what the group would usually do whilst minimising the effect of the observer. (Henry 1972) and (Vetere & Gale 1987) adopted this approach in their family studies which are detailed under that heading below.

Finally the complete observer would be making observations from an outsider's viewpoint, for example the Ofsted inspections of school activities or observations of families through a one way mirror, and hence do not fit neatly under the heading of participant observation.

Participant observation and ethnography

There is often confusion between these two terms and their usage. Indeed (Hammersley 1992) uses the term ethnography to be *'broadly equivalent to qualitative method'*. Ethnography is the study of a particular social group with the aim of finding out about the group's culture. Within that aim participant observation is often the method of choice, but not always exclusively so. For example, (Chatterji 1998) in her ethnographic study of a man with dementia uses both participant observation and reports from key others within his situation to construct her case. Hence it could also be argued that this is a case study, since it is the study of a person in a situation (Bromley 1986). The study presented in this thesis is ethnographic in that it aims to explore people at important points in their life, and that it also takes the viewpoint of the person with dementia – it seeks to understand from their perspective. However for me, to call it ethnography would seem to imply that to be a person with dementia is to be part of a sub-culture – perhaps true when viewed from the position of the medical model. I seek not to label in that sense but to try and explore the world of the PERSON with dementia rather than the person with DEMENTIA as Tom Kitwood so eloquently put it (Kitwood 1997). Hence I shall use the term participant observation to describe the methodology I used in my data collection for the case studies.

Participant observation with families in their own home

(Henry 1972) was an anthropologist who had an interest in families who had a psychotic member. He used participant observation as his method of choice in studying these families, adopting the observer as participant role whilst staying for weeks at a time. His final analysis of the data collected used a psychoanalytic framework for interpretation.

Drawing on his approach, (Vetere & Gale 1987) used this method in their study of families of school-refusing children by moving into the home and observing family behaviour for up to seven days. They recorded the events that had occurred each hour in the form of an observation diary by dictation into a tape recorder in private and then later analysed them using (Borgatta 1962) Interaction Process Scores. More recently, Gale and Seymour (in press) have been repeating this method in order to study older people.

Participant observation with people with dementia

There are an increasing number of studies using structured observation in the form of dementia care mapping to explore the worlds of people with dementia in formal care settings. However as (Stalker, Gilliard, & Downs 1999) note, there have been very few studies with people with dementia using participant observation. (Meade 1997) used this method in the formal care setting of a day centre for people with dementia. Participant observation in the person with dementia's own home is also rarely carried out. (Gitlin, Corcoran, & Leinmiller-Eckhardt 1995) used this method as a means of finding out about occupational therapy needs for someone with dementia. (Briggs et al. 1998) used observation in people with dementia's own homes, observing them for up to three hours at a time. However, more lengthy observations have not been carried out in people's own homes making this study unique in its approach.

The decision to use participant observation in this study

An earlier study for my MSc (Carr 1999) based on case study analysis of couples living in their own home where one had dementia involved my visiting each couple a few times for about an hour each time and asking questions about their lives. I started to notice that with many couples the carer would show me to the door and then start a new conversation in hushed tones saying *'they're not usually like this!'* For a short period of time people can put on an appearance, for example at an interview or meeting your new in-laws. People with dementia are no different in this respect and can put on their best efforts for short periods of time. Anecdotally this is well-known, from the home visit to assess needs to a neighbour popping in for a chat. Many carers are left exasperated (or relieved) that the visitor didn't see their relative with dementia in a rage or distraught. One man I visited as part of another study told me that his mother with dementia was very violent towards him, but when the psychiatrist visited she became a sweet little old lady. He eventually had to use a tape recorder to capture an episode of violence when he was forced to barricade himself in the bathroom. Similarly, as quoted in the introduction, (Bayley 1998) and (Seegmiller 2000) convey the feelings of the carer very effectively:

"Coming up to me the hostess says: 'Isn't Iris wonderful?' She sounds surprised, perhaps thankful that there is no squeaking or gibbering going on. I am conscious of a base sense of annoyance, even exasperation. People who see Iris on such occasions assume there must be nothing much to worry about. Suppose I were to say to our hostess, 'You should see how things are at home'. Thank goodness one cannot or does not say things like that at parties". (Bayley 1998)

"No one really understands until they spend extended periods of time with the person including the nights". (Seegmiller 2000)

This set me thinking about how I could get a better idea of what their day-to-day lives were really like. During a conversation with my supervisor I made a throw away comment about *'if only I could move in with the couples'*. This unlikely scenario became instantly attractive to me as a researcher and the seeds of participant observation were sown.

How participant observation was used in this study

Within the examples of participant observation detailed above there are a number of different ways of capturing data and analysing it. This section describes how this was carried out in both the pilot and main studies.

Pilot study

The pilot study consisted of spending one whole day with two families, one of whom features later in the case studies. During the stay I engaged in the same activities as the family, such as helping with chores, shopping, going to church etc. Data was recorded in the form of field notes made at convenient times throughout the day, for example on visiting the bathroom or whilst completing a crossword puzzle. At the end of the visit an extended 'diary' of the visit was made by dictating events of the day into a tape recorder. This process could take up to an hour. During the observation key aspects of behaviour were noted, as detailed in chapter three.

Lessons learned from the pilot study

I was nervous when visiting my first family for the day long observation. As the day wore on my feelings of awkwardness waned and the family also appeared to relax more in my company. I felt that the initial strangeness would inevitably be experienced by both parties and that a longer stay would enable me to see more usual behaviours within the family setting.

With both families I found that there was very little opportunity to take notes during the day, except when in the toilet. Hence I would need to be flexible about daytime note taking with the extended visits. I decided to take some puzzle books and newspapers to the longer visits so that I could take discrete notes. The end of day note taking, via dictation onto a tape recorder, was a vital part of the data collection and took about an hour in each case. I was mindful that for extended stays this would need to be done in my bedroom at the end of the day before going to sleep each night, which could be tiring.

One of the families, the Woodys, who feature in the case studies, had arranged for my observation day to coincide with a busy day for them. As detailed in chapter six, we had lunch at the local Alzheimer's Society meeting and then travelled to be at the launch of their daughter's new business venture. Hence for the main study I felt it was important to stress to the couples that they should not plan anything special, as I wanted to see a 'typical day'. It was hoped that an extended visit might lessen this tendency too.

On the positive side the pilot study showed that the different aspects I had decided to observe were useful ones in helping to illuminate the days events. As detailed in chapter three, I also felt that this data could be augmented by using dementia care mapping. Additionally the whole day visits provided the opportunity to see the person with dementia in many different social settings, for example in a church with a large congregation and at home with different family members. This would be a unique opportunity within the extended stays too.

Main study

A similar data collection method was used during the main study, building on the lessons learned from the pilot study. This consisted of visits to the families for up to three days at a time. Extensive diary notes were made again by dictation at the end of the day, in my bedroom. The amount of field notes which could be made during the day varied according to the activities taking place and this in turn varied from couple to couple and is discussed alongside each case study.

Limitations of participant observation

Reactivity

One of the main limitations of participant observation as a method of inquiry is that of reactivity. Both the reaction to having someone extra within the home changing the dynamics and also of knowing that one is being observed may play a part. However, it was hoped that during longer observations (up to three days) reactivity would be at its greatest during the start of the observation and that a return to more usual patterns of behaviour would be observed as the stay progressed. (Vetere & Gale 1987) note this possibility in their own observations and went on to use reactivity in a positive way by seeing it as an important source of working hypotheses in questioning why a certain mode of reactivity has taken place. In line with this way of thinking (Hammersley 1992) suggests that the key issue is whether the reactivity affects the results in ways that are relevant to the research topic.

The reaction a family has toward a researcher is going to depend on many factors. The researcher's age, gender, background and race to name but a few. For example, (Angrosino & Mays de Perez 2000) cites his own research with a woman from Saba (Netherlands Antilles) to illustrate this point. Two life stories were told to and by (i) Angrosino, a white, foreign, younger man and (ii) a Saba-born black woman of her own age. The different anecdotes which emerged showed that the woman had reacted differently to each researcher.

It must not be forgotten that reactivity can also operate in the opposite direction in terms of the observer's reaction to the family. Here the observer's own background, experiences and belief system are important. The debate, as seen by (Adler & Adler 1994) is that in becoming closer to the participants, an inevitable process when visiting for many days and over a period of two years, you will be able to uncover more intimate subjects or areas which the less familiar researcher would not have access to. On the flip side is the view that friendship may blind the researcher to unpleasant facts. As (Wong 1998) states, *'as our rapport developed, I began the dangerous slide towards treating my respondents as friends'.* I acknowledge that I, too, now view the couples in this way and still visit a number of them on an occasional basis. The reflective sections of this thesis will take up the challenge of exploring this side of reactivity for the reader.

Validity / reliability

An additional limitation of participant observation is that unless the situation is recorded and subject to checks by other observers, validity and reliability may be questioned. By using a variety of different methods for recording my observations such as, when appropriate and possible, dementia care mapping for parts of the observation I hope to be able to substantiate my observations within the case study presentation. Indeed (Bromley 1986) quasi-judicial case study method requires each claim to be substantiated in this way. In the case of dementia care mapping, as an advanced mapper I have had the opportunity to check the reliability of my observations using this tool against other qualified mappers in formal care settings.

Strengths of participant observation

As detailed in the section looking at my decision to use participant observation, when compared to brief visits, interviews or questionnaires participant observation allows the researcher a fuller picture into the daily lives of people with dementia and their carers and offers the chance for a more complete story to be told. As (Pointon & Pointon 1999) found in making their television programme in collaboration with a researcher who stayed with them, they were able to show *'warts and all'.*

In staying with the couples and sometimes meeting their friends and families during the course of my visits I was able to elicit the views of other important people in their lives. This I feel added an extra dimension to the research data which would not have been possible to obtain during brief interviews.

Ethical considerations

Some now classic studies, such as (Milgram 1963)1974) and (Zimbardo 1972), are taught in psychology classes largely for the ethical issues they raise. The British Psychological Society recognised the importance of having a code of conduct with respect to ethics for their members following a series of experiments, largely in the 60s and early 70s which have come to give psychologists a bad name within the general public. In their guidelines they cite deception, consent and confidentiality as key issues to be addressed ((The British Psychological Society 1997). This section on ethics looks at how these issues were dealt with within this study.

Deception

The couples were fully briefed on how the study would take place and what the results would be used for on a number of occasions. Firstly at the initial meeting over coffee at the day centre for some of the participants, within the information sheet provided to all, and then again at the initial meeting to further explain the study at their home. They were informed that they had the right to withdraw from the study at any time, including during my visits should they wish to. They were reminded of their right in this respect at each visit. They were given the telephone number of my supervisor and myself so that they could effect this right at any time. The arrangement for them to withdraw during a visit was that I would leave immediately on their request and that they would be contacted at a later date to see if they wished to discuss any issue further. None of the participants withdrew.

Consent and power issues

Consent was obtained from the couple on each occasion of visiting, in writing, and signed by the carer on the couple's behalf. This 'repeated consent' was felt to be particularly important in a longitudinal study of this nature.

Power dynamics, the relationship between the researcher and the researched, have been brought into question. This issue is dealt differently by the positivistic tradition and more hermeneutically based approaches, such as feminism (Wong 1998). The change from use of the term 'subjects', originally favoured by the positivist tradition to 'participant' reflects the change in acknowledging the important active role that the researched take in the pursuit of knowledge. Within this study I attempted to empower the people I would be observing by introducing myself as a student who was keen to learn from them as experienced carers.

Another side of the power argument highlighted by (Oppenheimer 1991) is that as researchers we receive valuable data from our participants, but what do they receive in return? (Stalker 1998) also cites this dilemma in her research with people with learning difficulties. In the case of dementia, for people taking part in clinical trials they may be offered some hope of relief from some of the symptoms, for example. Indeed (Sugarman et al. 2001) found that proxy consent by carers was given in the hope of some help for their relative from the trial medication, that doing something was better than doing nothing. In the case of people with dementia and their carers, in non-clinical studies, it is more likely to benefit future couples than themselves. However, (Pointon 2000) suggests that it is very therapeutic for the carer to be able to talk to someone from outside the family. Sometimes they feel more able to bring up issues which they would not feel comfortable discussing with family members. (Sugarman, Cain, Wallace, & Welsh-Bohmer 2001) cite altruism in terms of wanting to help others as the main motivation for proxy consent for non-clinical trials. Within this study altruistic motivations for taking part were cited. Mr Jackson spoke of wanting to help others whereas Mr Reed wished me to see what difficulties he was facing at first hand (in the hope that others could be helped to avoid this in the future). In the main study participants received £10 per day from the university to help with any additional expenses which they may have incurred during my stay. However, all of the participants seemed to feel uncomfortable about receiving the money – this was very clearly not their motivation. One carer wrote after receiving the money and exclaimed, *'we should have paid you!'*, another returned the postal order asking me to buy something for my new home with it and a final participant said they had given it to a charity their granddaughter was involved with.

Mr Jackson spoke of his enjoyment of having someone else to talk to during my visits, and in letters afterwards. Care workers at the Alzheimer's society had been trying to persuade him to send Eileen to the day care centre so as to give him a break. After my first stay he got in contact with them to give the day care centre a trial run. This seemed to work well for both of them and I was able to observe Eileen at the centre on a number of occasions. She enjoyed the company and would often lead the singing. More details of this are provided in the case studies in chapter six.

Confidentiality

The couples were assured that any identifying details would be changed when writing up the case studies so as to protect their confidentiality. In each case their names have been changed and similarly places of address.

Since four of the couples were recruited from the same day care centre they discussed my stays amongst each other and would often ask me how one of the other couples were doing. I felt slightly uncomfortable at this and framed my answer in vague and neutral terms so as to protect confidentiality.

Observation of 'private' areas

Before visiting I made it clear that I would not observe episodes of personal care. However, in some instances I did enter the bedroom of the person with dementia to help get them to bed. To allow the carer to struggle unaided was not acceptable when the nurse didn't turn up, for example. However, this does raise issues of safety for the researcher.

Safety of the researcher

In order to protect my own safety I arranged to phone my father each evening during my stay on my mobile phone. If he did not receive the call he was instructed to try and contact me at the couple's home (he always had their telephone number) before alerting someone at the university who could go to the address and investigate. This 'emergency' procedure was never required.

I had been instructed in methods for helping to lift patients during my voluntary work in a day care centre. However, I only helped the carer in this way if the nurses/paid carers did not arrive. Although this was not ideal and has implications for insurance etc, I would not wish to see a carer struggle and used my discretion and common sense.

Reflexivity – last but not least, the researcher

As mentioned in Chapter two, my original interest in dementia arose when having to choose a topic for my MSc dissertation. Whilst some of my peers were choosing subjects very close to their personal history I felt I should choose a subject of which I had no personal knowledge. This was my attempt at objectivity, a legacy from my days as an analytical chemist. Hence I avoided studying cancer, a popular choice in my class, since my mother had died from ovarian cancer in 1996. I quickly learned that studying people leads to unexpected situations which could not be predicted or prepared for and that objectivity was a pipe dream. On my first visit to a couple I would be studying as part of my dissertation I met Reg. Reg was caring for his wife, Eileen, who had dementia. This was the only detail I had about the couple prior to my visit. However, on meeting Reg in his hallway for the first time he explained that his wife Eileen also had other medical problems, including ovarian cancer. This threw me, although I could later see the superb irony! When I met Eileen I discovered that she had some of the audible symptoms of the cancer (stomach gurgling) that my mum had suffered. This couldn't have been a better time to confront what I felt would be an impossible family to study. It woke me up to the realisation that trying to be objective is not always possible – there will always be something that triggers an emotional response when dealing with people, but perhaps not such an emotionally raw subject. From then onwards I decided to make use of my subjectivity rather than to feel guilt for it or try to pretend it didn't exist or minimise it. To lay bare my own experiences and prejudices and how this may affect how I view the couples I have studied. Indeed (Vetere 1984) and (Ambert et al. 1995) feel it is very important to uncover any biases that the researcher may have by exploring what they bring to the observed situation. (Bochner 1997) goes further in suggesting that *'it is rare, indeed, to find a productive scholar whose work is unconnected to his or her personal history'*.

Just as I was hoping that I would see usual patterns of behaviour from the couples as they get used to my extended presence, I could not assume that I would be able to remain totally neutral in my role. Indeed part of the early visits were spent asking each other about our lives in a reciprocal fashion. To have tried to remain 'an observer' and not to disclose some aspects of my life when questioned would not have given the stay the 'normal feel' that it had.

I have included reflexive aspects within each case study. I have also tried to interpret these myself guided by a method described by (Peshkin 1988) detailed below, but by laying bare some of my own experiences the reader is also invited to make their own interpretations of how this may affect the research.

(Peshkin 1988) bravely and openly acknowledged how he *'stumbled upon'* his own subjectivity. As this struck a chord with my own experience of subjectivity in meeting Reg and Eileen I decided to use his method. Peshkin monitored himself during the research process and made notes of his feelings, for example situations he wanted to avoid. Within this he identified a number of different 'I's' and then occasions where these different roles were evoked as he related to his participants. He then used this information to look at how these roles may bias what he saw and what he failed to see or include.

Although I had had no personal experience of dementia I was familiar with some aspects of caring for a spouse. My father cared for my mother in the terminal phase of her fight against cancer. I saw how caring for someone who could no longer have the independence that she loved took its toll on both parties. But thankfully the cancer did not affect her brain and Mum remained the 'same person' until her death. I suspected that caring for a relative who had some aspects of their communication affected or whose personality changed radically would be very different.

However I was not unfamiliar with the effects of mental illness on the carer or sufferer. My Father's family have a strong history of depression and he has struggled with this himself during his life, including a couple of severe episodes which led him to a spell of treatment at the local psychiatric hospital – the most recent after my mother's death. Caring for and losing her clearly took its toll. I thought I had escaped the family depression, but I too had a spell in the local psychiatric hospital in 2000. I often describe this experience as the worst and best time of my life. It was an enlightening experience to be amongst people who had had all of life's social facades stripped away. What remained was the raw person, the essential being. I found my fellow inmates to be some of the kindest, nicest people I have ever met. I also experienced at first hand some of the prejudices and depersonalisation of which (Foucault 1988) and (Szasz 1974) wrote about. I was often reminded of these times when later observing in the day centres for people with dementia where I was able to sit with the residents during some of the activities. I clearly remember Maude turning to me during the reality orientation start to the day, reminding us what day, month, season it was and saying, *'they think we're stupid don't they?'*

On my arrival at the psychiatric ward I was prescribed an antidepressant, Cipramil, and, should I feel the need, a medication which would calm me down, Melleril. Despite my wretched state I remembered that this was a medication sometimes prescribed to people with dementia and I was keen to try it. Feeling agitated on the first evening I asked for a dose and was given 5mg. I was surprised by the reaction I had to it, starting with an initial manic euphoria where I went round and introduced myself to all my fellow patients. I then took to my bed and realising the peculiar reaction decided to try and sketch my room so I had a record of the effects. This I found in the morning after a long sleep. It had not been a 'normal' sleep but as if someone had clubbed me over the head. My drawing showed a very distorted view and perception of my surroundings. I vowed not to ask for further doses and wondered what this would make someone with dementia feel like, whose perceptions may already be altered. My final period in the hospital was a more pleasant one when I discovered that the dementia ward was directly below. I knew I must be feeling better when I found myself mapping from the window! (no doubt to the nurses a further sign of my madness (Rosenhan 1973)).

Although my experiences were very different from dementia I feel that my treatment as a person before and during my stay helped me to experience depersonalisation and its effects at first hand, and hopefully has made me more able to empathise with people with dementia. Although I feel that my stay in a psychiatric ward is not one to be ashamed of I made the decision not to disclose this to any of my participants. I did not want them to feel uncomfortable with this knowledge and whilst being willing to disclose some *information about my life felt that this was too personal.* Most of my disclosures in conversation during my stay were about my father and his childhood as he was of a similar age and had been brought up in areas where some of the families were familiar with.

Within the case studies my reflexive thoughts are noted for the reader to make of them what they will. My hope is that as (Finlay 1998) describes:

'Reflexivity offers a tool where the problem *of subjectivity in research can be turned into an* opportunity'.

Chapter five

Methodology:
Social death: development of a measure

Introduction

Social death was highlighted in the literature review as a possible factor affecting carers' style of care. As the literature review pointed out, this is a little researched area particularly in the field of dementia care. (Sweeting & Gilhooly 1997) designed a short interview schedule aimed to measure belief in social death. They used this to compare with brief observations measuring behaviour with respect to social death.

This research took a different approach to the measurement of social death; Firstly a critical incident diary, aimed at eliciting beliefs on social death, was piloted. As detailed within the chapter, this method was not found to be ideal and the research turned to the thematic analysis of six biographies written by carers of a relative with dementia to elicit key areas related to social death. This analysis informed development of an interview schedule and directed observations made during the visits. Both beliefs and behaviours were then compared, as (Sweeting & Gilhooly 1997), within the case studies.

This chapter sets out the journey to develop a measure for social death, from the initial critical incident diary to the final interview schedule.

The critical incident diary study

Background

Diaries have been used in a number of different areas of psychology to report events shortly after they have happened, thus increasing the accuracy in reporting which is often lost in retrospective interviews or accounts, for example, (Gill et al. 1997); (Kendall 1999;Pennebaker 1993;Punamaki 1998;Schimmack & Diener 1997;Shiu 1999;Stephenson et al. 1997;Tidwell, Reis, & Shaver 1996); Coxon (1988) and Tidwell et al (1996). In exploring the day-to-day lives of people with chronic problems or medical conditions the diary method can help to illuminate details of importance to the diarist which may be missed by other data collection methods, for example, Clarke (1999), Gill et al (1997), Kendall (1999) and Stephenson et al (1997). It allows a window into the lives of people psychologists are interested in exploring, from their own perspective.

The diaries, as well as being of great interest to the researcher, may proffer benefits to the diarist too. Pennebaker (1993), in his review paper, indicates that writing about emotional events can have positive health benefits for the writer. He cites studies which have shown a rise in immune function for diarists and a reduction in the number of visits they made to their GP. It would appear that the greatest improvement in health was shown by those who expressed anxiety and sadness in their writing. This may be particularly relevant for carers of people with dementia.

Pilot study of carer's critical incident diary

This pilot study aimed to develop a carer's diary which would be used as one source of data in exploring the carer's perception of what it might be like to have dementia and the phenomenon of social death.

A critical incident diary was employed to illuminate the day-to-day lives of carers of people with dementia. To try and elicit information about beliefs of social death, as well as description of the events, the diary also requested information from the carer about what they thought their relative with dementia felt during the event.

Date:

Please record below any events which happened today while you were caring for your relative which you felt were particularly good or particularly bad for either yourself or your relative.

What happened?

How did you feel?

How do you think your relative felt?

Please write here anything else you would like to say about the event -

Four participants, who were caring for their relative with dementia at home, were found with the help of the Thornhill Research Unit at Southampton. Each carer was met in their own home by the author and asked to complete the diary every day for seven days, then to return it by pre-paid post. A follow-up visit was then made to discuss the events recorded in the diary and any problems they had in completing the diary.

Unfortunately, although providing an interesting insight to the day-to-day lives of people with dementia and their carers, the diaries were not found to illuminate the area of social death and perception. The section which was hoped to pick up on this asked the carer to say how they thought their relative felt about any particular event that they had written about. It was expected that if the person with dementia was thought of as 'socially dead' then their carer would assume that they did not have emotions / feelings about any incident. The carer's reported answers such as:

'I'm sure Jim felt happy and relaxed'
'I don't think Jim felt anything very special'
'Mum didn't feel so well this morning'
'confused'
'very confused'

It became clear that this one question was not going to reveal the presence or absence of social death, and that this was far more complex and hence required a more complex method for illumination. It was felt that a more detailed look into the nature of carer's perceptions of what may be going on inside the minds of their relatives with dementia was needed. In addition the carers that had volunteered to take part in the pilot study had been keen writers and it was felt that for some carers this may not be such an easy task to carry out as well as to take part in observation. This initial and somewhat naïve attempt at illuminating social death beliefs required a much better defined foundation before being used with carers.

Thematic analysis of biographies

A biography can provide detailed information on thoughts and emotions surrounding particular incidents or episodes in a person's life, and it was decided to make use of the increasing availability of carer's biographies to this end. Six biographies written by carers of a relative with dementia detailing this episode in their lives analysed: Remind me who I am, again (Grant 1998); Scar tissue (Ignatieff 1992); Iris – a memoir of Iris Murdoch (Bayley 1998); Iris and the friends, a year of memories (Bayley 1999); Life with big al (early Alzheimer's) a caregiver's diary (Seegmiller 2000) and Living daily with dementia (Ashman 2002). For each book any passage alluding to perception of what it might be like to have dementia was transcribed. These transcriptions were then subjected to a thematic analysis to elicit the different aspects of perception, and their relation to social death. These themes were drawn from existing theoretical ideas, such as malignant social psychology, using deductive coding, but also via inductive coding from the raw text itself (Joffe & Yardley 2003).

The themes elicited were as follows (for an example from the texts see Appendix four):

- Malignant Social Psychology / positive person work
- Insight / awareness
- Person with dementia and emotions / behaviour
- Person with dementia as changed vs not changed
- The relationship between the person with dementia and carer
- Recognition
- Communication
- Social death
- Mind-body interaction
- Dementia and the self
- Metaphor and dementia
- Dementia as loss
- What is it like for the carer?

These themes are further explained and illuminated by looking at their sub-categories below:

Malignant Social Psychology / positive person work

One of the most immediately noticeable aspects of the biographies was their fruitful supply of examples of both malignant social psychology and to a lesser extent positive person work:

Malignant social psychology

- *Deception (even though good intentions)*
- Invalidation
- Carer feels person with dementia feels betrayed
- Person with dementia as not a person / Human vs not-human / object, ‘us’ vs ‘them’
- Gradual loss of being human / a person
- Child-like
- *Parent-child relationship*

Positive person work

- Carer treats the person with dementia as same person / still as an adult / human
- Person with dementia develops strategies to deal with their difficulties
- Others can learn from the person with dementia

Finally within this theme were also examples of the carer wondering if the way they care has an effect on the person with dementia and further as seeing their relative’s quality of life as their responsibility:

- Does the way we care help? (carer wonders)
- Carer responsible for the person with dementia’s quality of life

Insight / awareness

Following on from the carer wondering if their style of care had an effect was the questioning of their relative's awareness of 'what goes on in their head?'

- Carer uncertain (and wants to know) about what is going on in the person with dementia's head / if they understand what remains / whether insight
- Person with dementia still knows what's going on
- Carer thinks person with dementia has some insight / sometimes
- Carer thinks person with dementia doesn't know what's going on - or do they? – dilemma
- Person with dementia no longer 'taking things in', 'failing to grasp'
- Person with dementia not in touch with reality / losing touch /different reality

This thinking was often fuelled by lucid moments and led some carers to fear that there was indeed insight.

- Person with dementia has lucid moments (lucidity as terrible)
- Reality as nightmare
- Hopes the person with dementia doesn't know what's going on

Person with dementia and emotions / behaviour

Linked to the above were many examples of the range of emotions and behaviour of the person with dementia. Some instances suggested that feelings and emotions were not remembered and hence didn't have an effect – something which may affect caring style. However this was counterbalanced, albeit less frequently, by some carers acknowledging emotions were still very much present and real for the person with dementia.

- Person with dementia has poor quality of life
- Life passes person with dementia by
- Person with dementia lives only in present
- Present moment also forgotten
- Even current emotions forgotten quickly
- Person with dementia doesn't remember or understand therefore protected from feelings / has no cares
- Person with dementia still has emotion/feeling
- Rational reason for actions – not just due to the disease
- Emotions due to symptoms of dementia not the person
- Person with dementia has mood changes
- Person with dementia as frightened
- Person with dementia as confused / bewildered
- Confused by night and day
- Person with dementia as lonely / isolated / alone
- Person with dementia as agitated / anxious / upset / concerned / depressed
- Person with dementia as suicidal
- Person with dementia as annoyed / aggressive
- Person with dementia needing to feel safe
- Person with dementia as suffering
- Carer thinks person with dementia would like to escape
- Person with dementia as attention seeking
- Person with dementia as difficult
- Person with dementia as slower on the uptake, slowing down in processing
- Person with dementia as having lost skills
- Person with dementia as unpredictable
- Person with dementia as happy

Person with dementia as changed vs not changed

A key theme was whether the person with dementia had changed or not. It is thought that a change, possibly even perceived as their becoming a stranger, as affecting beliefs of social death.

- Person with dementia as different vs same person
- Person with dementia as a changed / different person
- Person with dementia as a stranger
- Person with dementia still the same in some senses

The relationship between the person with dementia and carer

Also important was the relationship between carer and person with dementia and whether dementia was perceived to have changed this. Again the two opposing ends of the spectrum can be observed.

- Still same relationship together vs different
- Person with dementia and carer as closer
- Person with dementia and carer can no longer share same things as before

Recognition

Recognising self or others could add an extra dimension to the belief of social death, with non-recognition making it more difficult to preserve non-belief in social death.

- Recognition of others vs non-recognition
- No longer recognising self

Communication

The way the person with dementia and carer communicate may provide an insight into the carer's belief in social death, for example some seeing it as futile, difficult, or still possible with help.

- Pointless for various different reasons
  - asking questions
  - visiting
  - trying to communicate
  - taking him to Dr because he won't understand the questions
- Person with dementia no longer understands words
- Communicating with person with dementia is like communicating with foreigner
- Communicating with person with dementia is difficult / takes time
- Person with dementia is on a different planet / in a different place
- Person with dementia is still trying to communicate
- Person with dementia relates well to children and animals
- Carer has to decipher in order to communicate
- Some memories still intact
- Person with dementia repeats

Social death

There were many examples of social death itself in pure form, stated explicitly.

- As good as dead
- Carer as alone (even though the person with dementia is there)

- Already dead
- Carer saying goodbye before the person with dementia was dead
- Person with dementia talked about in third person
- Use of past tense to describe person with dementia, even though they were still alive
- Between life and death
- Death as a relief / good thing
- Person with dementia wanting to die

The following themes are seen as carers' perceptions of dementia: its link with mind and body; its effect on the self, on personhood; and finally as metaphor, where perceptions are eloquently and vividly described.

Mind-body interaction

- Mind as separate from body
- Body present, mind/memory not
- Mind somewhere else
- Mind shutting down / declining
- Disease taking over the mind

Dementia and the self

- Person with dementia as shell of / Ghost of former self
- Person with dementia as leaving the self
- Dementia as an illness of self
- Self / identity vs no-self remaining, gradual loss of

Metaphor and dementia

- Terrible wilderness
- Shrinking lump of meat
- Permanently turned off at the mains
- Soft in the head
- Software in the computer is all muddled up
- On a journey
- An insidious fog
- Sailing into the darkness
- Before all the lights go out
- As poor radio-telephone reception
- Dr Jekyll and Mr Hyde
- Corridors of confusion in the mind
- Dementia as madness
- Vacant / vacuum / empty
- Dementia as a dark place
- Dementia as tragic
- Dementia as stigma

BUT

- Dementia not as frightening as we imagine

Dementia as loss

- Dementia as something lost vs something remaining
- Lost dignity
- Dementia as more than just a loss of memory

What is it like for the carer?

Finally, during reading the biographies a theme about what the experience was like for the carer emerged. It was felt important to include this as it helped to place the carer's beliefs about social death into some context.

- Carer as alone
- Much worse for the carer!
- Person with dementia drives carer to violence / infuriates
- Others aren't aware of the difficulties
- Person with dementia as having public and private images

Developing an interview schedule

The major themes from the above analysis were used to help create an interview schedule for the carers which, it was hoped, could allow for the carer's thoughts and examples to be elicited on these key themes. With actual examples it was felt that both behaviour and beliefs in social death could be examined alongside, and then compared with, observational data from the visits. All themes were used to guide the analysis of data to help understand the carer's perception of dementia and hence their beliefs of social death with respect to their own relative.

Interview schedule

Can you remind me - when did you first notice XXXX's illness?

What did you know about dementia then? (knowledge)

Had you had any experience of other people with dementia?

Do you feel XXXX has changed in any way during his/her illness?

What was your relationship like with XXXX before his/her illness?

Did your relationship change when he/she became ill? (were you closer in any way, further apart, or the same as before?)

How would you describe XXXX's quality of life since his/her illness?

What has communication been like between you and XXXX?

Does XXXX *recognise you and your* family?

Does XXXX ever have any lucid moments? Can you give an example? What do you think this may mean?

Do you think XXXX has any insight into his illness? If yes please give an example.

Does XXXX seem to know and understand everything that's going on?

Does XXXX ever talk about what's happening?

What is it like for you caring for XXXX?

What do you think it is like for XXXX?

Chapter six

The case studies

Introduction

This, a key chapter in the thesis, looks at the lives of five couples and their journey with dementia. First we meet Mr and Mrs Woody, a couple in their seventies who live on a large farm with their extended family nearby. Gilbert has vascular dementia and is cared for by his wife, Patricia. Despite his speech and mobility difficulties, Gilbert enjoys a good level of well-being, still being a valued member of his large family. Patricia is an inventive and able carer who looks after both his physical and emotional needs. Their story is a positive one from which we can learn many useful lessons in good dementia care. Mr and Mrs Dudley, a few years younger than the Woodys, also managed well despite their difficulties. Neil, who had frontal lobe dementia, had held a high and respected post during his working life. His retirement was cruelly cut short by dementia but his wife, Claire, helped to make his final few years as comfortable as possible. For Mr and Mrs Archer and Mr and Mrs Reed the story is not so positive. Monty and Frances Archer, a couple in their eighties, struggle with their situation. Monty has vascular dementia and the insecurity of previous experiences in his life show through in his current circumstances. Frances finds his demanding nature as difficult as ever and tension is high. Mr and Mrs Reed, Thomas and Anne, again illustrate the difficult side of dementia. During the last year of her life Anne spent much time in a state of ill-being as Thomas struggled to care. However the final couple, Mr and Mrs Jackson remind us that there can be growth through adversity. Both in their late eighties, Jim and Eileen are still very much in love. Eileen has had Alzheimer's Disease for 13 years and Jim has cared for her admirably.

Within the case studies each couple is introduced fully and their situation summarised before the details of each visit are unfolded. Full details of the final interview with the carer are provided so that their views on social death can be ascertained. A synopsis is then presented for each visit considering the following aspects:

The person with dementia's well/ill-being

This was investigated by a variety of means to provide a number of different sources of evidence. Firstly the person's well and ill being was assessed by using indicators of well and ill-being, (Bradford Dementia Group 1997). For each visit examples of each category were presented and an overall score calculated for each. The scores could be reviewed to look for changes over time.

Although Dementia Care Mapping (DCM) has been used extensively within formal care settings there is, to date, no literature on it's use in the community in informal settings. For each visit, where possible, data for DCM is presented and it's use in this setting examined and discussed. Behaviour profiles showing the proportion of time spent in each category are shown graphically for each day, and then summarised over the whole time of the visit. Similarly, graphs showing the well-being / ill-being values are given. Whilst DCM enables the reader to see how the person with dementia spends periods of their day, because it would be too labour intensive to do throughout the stay, the portions of time spent mapping are necessarily selective. All mapping periods were carried out whilst in the person's home. The time spent mapping needs to be considered alongside non-mapping periods to see how these compare, hence all behaviour category codes not recorded during mapping are discussed individually for each day. In addition some of the coded behaviours are discussed, where appropriate, to illuminate their use. In addition, examples of specific instances of elements of malignant social psychology and positive person work, summarised in (Kitwood 1997), and also used in DCM reports are presented.

Finally a number of aspects which illuminate well-being, drawn from (Sabat 2000), are explored.

The carer's perception of what it may be like to have dementia

Any aspects noted during each visit are presented to help build up a picture which is further explored in the perception interview.

Other measures

The Bristol Activities of Daily Living (BADLS) (Bucks et al. 1996), and the Behaviour Rating Scale for Psychological and Social Problems (BPS), (van Loveren-Huyben, van der Bom, & Bronts 1988) were completed after each visit by the carer and separately by the author. This enabled me to compare the carer's view with my own. Individual scores of cognition, social contact and mood on the BPS were used as further evidence in the case study.

Longitudinal profile

Here the key issues drawn from the longitudinal dimension of the study are presented.

Résumé

The final section in each case study encapsulates the key aspects gleaned from the visits.

Data presentation

Since the couples were visited up to four times, with stays of up to three days in length over a two year period, the data are necessarily sizeable. Whilst the key aspects are presented within this main volume, interested readers can see a fuller picture by referring to the second volume, which presents the data in its complete form in appendices detailing examples of indicators of well and ill-being, elements of malignant social psychology, positive person work, carer support for intact abilities, validation of emotion by carer, politeness strategies, aspects of selfhood and carer's perception of what it may be like to have dementia. In addition graphs for each day of each visit are featured for well-being/ill-being scores and behaviour category codes of dementia care mapping are presented. The reader is directed to these appendices as appropriate.

Mr and Mrs Woody

Background

The Woodys live in Farnham on a beautiful farm. Patricia and Gilbert, both in their 70s, live in the farthest Farm House from the drive which connects them to the village. Their daughter and her family live in an adjacent farm building which has an adjoining door for ease of visiting. One of their sons and his family live a little farther away, but in the same village, so they have two families around them for support. They also have another two daughters, one who lives in Sussex and the other in Australia. All of their children and grandchildren play an important role in this very close and supportive family. As well as family support the couple have also received help at various periods over the years from professional carers, the local Crossroads team, the local Alzheimer's Society and an Admiral Nurse.

I first met the Woodys through their local Crossroads team when I was piloting the participant observation method. Being used to a busy household with many different people around Patricia didn't feel in any way anxious about having me as an 'observer'. I also found the rest of the family quite accepting of my role as observer. Coming from a small family myself I found this reaction quite surprising. They reminded me of my friends from larger families whom I used to visit during my school days. I was always envious of the bustling 'comings and goings' of larger families. Another mouth to feed just meant adding a few more potatoes to the pot, whereas a visitor to a small family was a major occasion.

In total I visited to observe the Woodys on four occasions from November 2000 to November 2002 but also met up with Patricia at an Alzheimer's Society seminar, at her invitation, and visited to complete the final interview at the farm.

Gilbert was a farmer and also spent many years as head of a section in a large corporation. Originally in the Canadian Army he is a very tall and well-built man. Although Patricia is also tall, helping him with physical care tasks could be a daunting job. He was diagnosed as having vascular dementia in the mid 1990s. Patricia had first noticed that he was becoming confused and disoriented at night if he woke. A BUPA medical check showed he had heart rhythm abnormalities and he was prescribed Warfarin. However it was on visiting their daughter in Australia that Patricia noticed his confusion had worsened. On returning to the UK she sought help from their GP who advised a CT scan. Unbeknown to Patricia when the doctor telephoned with the scan results Gilbert was listening in on another phone extension. This shows that at this early stage he was aware that something was wrong and wanted to find out for himself what was going on. As Gilbert listened in the Doctor told Patricia that the good news was that he did not have Alzheimer's Disease, however he did have vascular dementia. When she walked into the room Gilbert was listening in from he announced *'well that's it then'*, and has not talked about his illness or diagnosis since.

The close proximity of their family enabled me to also spend time talking with others about Gilbert. This proved very useful in obtaining corroborating evidence to help compile the case study and to get a clearer overall picture of his family life.

Patricia struck me as a very competent, resourceful woman. Her positive outlook on life enabled her to think through problems and provide solutions where others may have given up. She felt that being 'well off' helped this process enormously but I felt that her underlying motivation and enthusiasm were the catalyst. Her ingenuity enabled Gilbert to continue to enjoy a number of activities despite his illness. For example, as a farmer he was used to patrolling round his land. Someone with his diagnosis and showing clear signs of spatial confusion would often have to be either accompanied on the walks or prevented from doing so. However, with the aid of her grandson, Patricia searched for and purchased an electronic tracker device from the internet which enabled her to see where he was within a certain radius of distance via a contraption which he wore on his belt. As he was well-known in the village his neighbours would often spot him out walking and invite him in for a cup of tea, whilst telephoning Patricia to let her know of his whereabouts. This enabled him to retain his identity as the person 'in charge' of the farm and also to have social interaction with his neighbours.

After a hip replacement in the late 1990s his mobility became much more restricted. However Patricia bought a custom made wheelchair and later acquired a converted van which took Gilbert in his wheelchair in the back. The van had large windows from which he could look out on his journey. This enabled them both to continue shopping together, visiting friends and also to attend the local Alzheimer's Society luncheons.

Her unrelenting resourcefulness, despite many hitches with social services and other care agencies, undoubtedly enabled Gilbert to retain some of the activities which were key to his identity. My observations of Patricia and Gilbert lead me to conclude that she still treats Gilbert as a person, that through her he was enabled to retain his personhood and, as such, spend most of his time in a state of well-being.

In terms of her perception of what Gilbert experiences with dementia she behaves towards him as if he can still understand and is the same person despite his cognitive difficulties. There are numerous examples of this throughout the visits. When asked about her beliefs she felt that sometimes he understood, that she was not always certain, but that she should behave as if he understood in case he did. She cited examples which led her to believe he still understood much of his situation and these are also detailed in the following accounts of my visits.

Visit 1, November 2000

This visit was carried out as part of the pilot study looking at participant observation, and hence was only one day long with no overnight stay. However at the time of this visit Patricia asked if I had wanted to stay over so as to avoid a long journey home at the end of the day. This gave me encouragement to believe that other participants may be willing to allow me to stay.

On my first visit to this amazing couple I felt I instantly warmed to Gilbert who, whilst Patricia was chatting to me at some point, winked and made me laugh.

This first visit took place on a Tuesday, at Patricia's request, so that I could accompany them to the local Alzheimer's Society lunch and talk with others in a similar situation. Although the morning was quiet and uneventful the rest of the visit was quite hectic. After the lunch we drove about 30 miles to join their youngest daughter and husband at the launch of their new delicatessen. This meant that I was able to see Gilbert in a number of different social situations throughout this one day visit. On returning home Patricia took me round to meet the rest of her family, who live next door, whilst she prepared dinner. This enabled me to get a variety of views about Gilbert from his relatives. After dinner with the family, Gilbert, Patricia and I retired to their lounge to watch a film on DVD before I left for home.

I felt much more at ease with Patricia and Gilbert compared with the first family I had spent a day with as part of the pilot study, possibly because it wasn't my first observation but also, perhaps, because I had learned from the first observation that it is inevitable that some family members will want to ask about my own life. This time when it happened I felt more relaxed, rather than worrying that I was not witnessing a 'normal' day in their lives, but that this was being coloured by my presence. I soon came to the conclusion that the sharing of personal information was inevitable and a vital part of the stay which helped to form a good relationship with the family and to put everyone at ease.

I asked Patricia if the day I had observed was a typical day and she replied that they wouldn't usually go out as much as we had. The opening of their daughter's shop had been an unusual event. I hoped that by observing them over a longer period I would witness some more typical days and made a mental note to stress to families that they should not arrange to do anything special because I am visiting. The Woody family had asked that I observed on a Tuesday so that I could attend the Alzheimer's society lunch as this would be more 'interesting' to me. Persuading caregivers for people with dementia that researchers are interested in their day-to-day lives is a difficulty which (Briggs et al. 1998) also acknowledge in their observational study.

Whilst we were in the shop I spent about an hour solely in Gilbert's company while Patricia talked to her daughter. I found 'looking after' Gilbert – helping him up and down the small flight of stairs, preventing him from knocking things over and playing with a small plastic dinosaur he had found completely exhausting. This made me think about what it would be like to look after Gilbert on a full-time basis. What I found most difficult was that communicating with Gilbert involved great effort and thought as opposed to the well-practiced art of conversation in every day interactions with people with intact speech.

I felt very unprepared when Patricia took me round to her daughter's next door to speak to their grandchildren and found I had to think on my feet to a large extent. Being in 'psychologist' mode, being 'on duty' for over 10 hours was very tiring. I concluded that observing families for three days would be very challenging.

Visit 2, May 2001

I arrived on a Tuesday morning and as the weather was fine we sat outside drinking coffee. The Woody's were having their outdoor pool cleaned so we spent a little time walking out to see how the workmen were progressing. Gilbert was able to walk with a stick, or someone's arm for support, but was much less mobile than six months ago. In November I had walked alongside Gilbert when we visited his daughter's shop. This time he walked along holding Patricia's arm, or a stick, his pace being much slower, far less steady and more 'shuffling' in gait. Gilbert has very limited speech remaining and communicated in the same manner as at my last visit, six months ago.

This was a very quiet day in comparison with my last visit. We sat out in the sun and had lunch and then retired to the lounge where Patricia and Gilbert dozed and I did one of my puzzles and made some notes. In the early evening the grandchildren came round, followed by an old friend of Gilbert's and we all had dinner together. Here I was able to observe Gilbert's reaction to seeing someone from his past, who he clearly recognised.

The next day, Wednesday, we went out for a short drive in the morning to fetch some disinfectant for the pool. After lunch Gilbert had his hair cut by the visiting hairdresser before retiring to the lounge for his afternoon sleep. Patricia went out shopping in the afternoon whilst I sat with Gilbert. Later on the family arrived for dinner as usual.

They have a 'woman who does', Teresa, who I didn't meet at my last visit. Teresa has worked for the family for approx 30 years and has a very good relationship with Gilbert. I was able to observe Teresa and Gilbert together on my final afternoon's stay when Patricia went out to play golf.

Patricia still receives help from the local Crossroads team, but the Admiral Nurse no longer visits. She had asked Patricia if she would mind if she just kept in telephone contact rather than coming out to see them both as she had now got a very large client base. Patricia had replied that she didn't mind but confided that she missed the nurse's visits. The district nurse from the local GP's surgery now visited Gilbert to check on his blood levels of Warfarin. However, she didn't appear very reliable and during my visit Patricia had to phone the surgery twice to see why she hadn't turned up. But Patricia feels that there are people worse off than themselves so does not like to complain too much.

Length of stay

During the three days I felt that I was beginning to see the same sort of pattern of behaviours presenting. This, coupled with the length of time that a researcher can sustain observation and also the length of time that a family can cope with having another member in their household, suggests that three days is an appropriate duration.

Settling into the stay

This time I didn't feel I settled as quickly as I had done with the Jackson's, who I had recently visited. Patricia, Gilbert and I sat outside in the sunshine drinking coffee. I felt Patricia settled into my visit almost immediately as she was used to having lots of people around her. Perhaps as I usually live on my own and am an only child I am not used to the hustle and bustle of a larger family life.

However during the first afternoon of my stay Gilbert had settled in his chair for an afternoon nap, Patricia was sitting nearby writing up some notes from the local parish meeting and I was able to relax and carry out some dementia care mapping whilst completing some of my puzzle book.

I felt much less tired at the end of the day than when staying with the Jackson's. Possibly because this was not my first visit and possibly because I was suffering from caffeine withdrawal headaches at the Jackson's.

The last time I was at the Woody's I didn't have to help with any physical aspects of Gilbert's care, apart from walking with him to his daughter's shop. This time, perhaps because of his decline in mobility, I felt I should offer to help in some way when Patricia was trying to get him in and out of his chair. I felt quite awkward about this as I didn't want to intrude on care if she felt it was something she should do alone. However over the stay I noticed that when others were around they would always help with this aspect of care. On the first morning when Patricia was walking with Gilbert he caught his foot on a raised bit of path and fell over. Being such a heavy man we were unable to lift him and she went and got the gardener, who seemed quite used to this. Gilbert was also not upset by this and, after the initial shock, he laughed. Teresa later told me that he was found laughing on his back in one of the fields recently when Patricia had let him walk unaided. I felt Teresa thought that this was very risky, but I feel that Patricia is allowing and encouraging Gilbert to use his still intact abilities where possible.

Gilbert is still able to recognise important people in his life, and appeared to recognise his friend Barry when he came round for dinner. I wondered what he thought about my presence although the family had recently had a friend of their son's to stay for a while and often had visitors. At one point on the first morning Patricia noticed that Gilbert was staring at me and exclaimed, *'gosh Gilbert you are staring darling! – I don't think he's sure of who you are'*. She then explained to him who I was and where I was from.

One of the most pleasant aspects of my stay was that I had a whole suite of rooms to myself, including a bathroom, on a different level from the rest of the family. When I retreated to this area I felt I had my own space again which, in my view, is important during intensive research of this kind. In the Jackson's small house I still felt very close to the rest of the family, and not in my own space. At both visits I took my sleeping bag to save washing extra bedding. Patricia was particularly surprised when I told her this at the end of my stay as it was Teresa who showed me to my room on arriving. I feel that there is also something comforting about zipping myself up in my own sleeping bag at the end of the day while in someone else's home.

I also enjoyed all the food that Patricia cooked. She knew that I didn't eat meat but that I was happy to eat fish and she prepared some super fish dishes. On the final day she cooked myself and one of her grandchildren, who was also a veggie, some excellent veggie sausages and mash. Their diet was much more like my own than the Jackson's, with the exception of the full fat milk which they used (possibly as ex-dairy farmers they preferred this). In addition they always poured a drink (G&T) at 5.55pm and had wine with their meal. This was very welcome, as my recent stay at the Jackson's had been three 'dry' days!

One of the more negative aspects of my stay, personally, was that I felt very much a 'commoner'. Patricia and her family speak in very refined English, unlike myself. At times I found the confidence of their grandchildren, educated at public school, overbearing. On one occasion the children spoke of 'common people' – exactly what I would label myself. This made me feel uncomfortable in their presence. I struck up a rapport with Teresa, feeling she was more on my social level.

On the final day during dinner Patricia's daughter, Ann, offered to feed Gilbert, allowing Patricia to sit amongst the grandchildren. Patricia said that it was a long time since she had sat down that end of the table, so this is obviously not a usual occurrence. Perhaps Ann did this to give her Mother a rest, or perhaps to look more favourable to myself.

Visit 3, October 2001

As before, I enjoyed my visit to the family and did not feel as tired during this visit. This time I arrived on a Monday afternoon. It was pouring with rain and I met Patricia who was just returning from a game of golf. Gilbert was asleep in his chair. The day panned out as before with a quiet afternoon for Gilbert followed by dinner with the extended family. His mobility problems had worsened, Patricia describes him as ‘physically insecure’, and he now requires a wheelchair to get to the dinner table, rather than walking with a stick. Similarly getting him to bed, as he is a large man, requires two people. Ann usually comes round to help Patricia with this, and I witnessed their excellent rendition of the conga – Patricia in front, Gilbert in the middle and Ann supporting him from behind! As always, fun is brought into Gilbert’s life by his family, even in this case during a routine task of helping him go to bed. Patricia has also acquired a hoist to help with certain physical tasks when she is on her own with Gilbert.

I was rather thrown when Patricia asked me to invite my father for dinner on the second evening, knowing that he would not want to come – he does not enjoy large social gatherings. I also felt I would be distracted by ‘looking out for him’ as I do when we are together at events he does not enjoy! As this invitation was totally out of the blue for me I was not ready with a pre-prepared excuse! I phoned and asked him the next morning correctly guessing his response! I told Patricia that he was a very shy man and would not feel comfortable. It struck me the large difference between my own family and Patricia’s. Coming from a small family (myself, Mum and Dad) having any extra person round for dinner was a major event. However, Patricia regularly cooks for at least eight, so another mouth appears to be no problem, in fact is positively welcomed.

They have a new carer, Mel, who I met on the second day. Mel arrives in the morning and helps Patricia to get Gilbert up. Mel and I spent the morning sitting at the kitchen table with Gilbert, she chatted while Gilbert dozed on and off and I read the paper. Patricia, Gilbert and I headed off to the regular Tuesday lunch with the local Alzheimer’s Society. Due to his increasing mobility problems, now requiring a wheelchair, Patricia has bought a second hand converted van with windows around the roof.

Gilbert is wheeled into the back of the van in his chair and can see out of the windows as we travel.

The afternoon was spent in the lounge, with Gilbert asleep in his chair. At dinner that evening one of Patricia's now single women friends arrived and it became clear that my father would have been 'set up' to meet this woman! Just as well I had made his excuses – she was most definitely not his type! After all the guests and family had left we returned to the lounge to watch Porridge on television. I helped Patricia to get Gilbert to bed that night as Ann was out with friends.

The final day began as usual with Mel arriving and helping Patricia to get Gilbert up and dressed. After a short time sitting in the kitchen listening to Foster and Allen tapes we drove to the local shopping centre. Here I was able to see how Gilbert fared whilst out and about in his wheelchair, manoeuvred by Patricia. The centre is well-designed for wheelchairs and we had a relaxed lunch overlooking the outside water area. After returning home we sat in the sun for the afternoon and I left before dinner.

Visit 4, May 2002

For the first time in my research I had forgotten my tape recorder and so had to hand write the notes during and at the end of the days. I felt a sense of sadness at this being the final visit, although both Patricia and I agreed we would like to remain in touch.

This was to be a slightly shorter visit for a number of reasons. Firstly, Patricia had a number of relatives visiting from Australia during May and, secondly, I had taken on more teaching work so arranging mutually convenient days proved difficult.

I arrived on a Friday morning and was greeted by the Crossroads carer, Ruth, who in Patricia's own words *'can talk the hind legs off an elephant!'* We all sat outside in the sun and waited for Patricia to return from a shopping trip. As usual I spent the afternoon in the lounge with Gilbert as he dozed in his chair. After drinks at six the family arrived for the evening meal. Patricia, Gilbert and I watched Inspector Morse in the evening – both Patricia and Gilbert dozing on and off during the episode. I helped Patricia to get Gilbert to bed and noticed how much more difficult it was this time, with his mobility even more impaired.

Saturday was a beautiful May day and Patricia, Gilbert and myself went out around the village to sell neighbours tickets for the Golden Jubilee party. We went to their son's house for lunch – he lives in the village – and had some difficulty getting Gilbert inside the house as it doesn't have ramps. The afternoon was spent at the local May fair watching the May queen procession and browsing the stalls. I left the family when we returned from the fair later that afternoon as Gilbert slept in his chair in the lounge.

Interview with Patricia, Nov 2002

How it began

AC *When did you first notice Gilbert's illness?*

Patricia reminded me that she had first suspected that something was *'not quite right'* about 6 years ago in that he would lose his bearings if he got up in the night. She arranged a BUPA check-up for him where they discovered he had some heart rhythm abnormalities and he was prescribed warfarin. However, it wasn't until a year later when they went out to Australia to visit one of their daughters that he became very confused and on returning home their doctor advised a CT scan. Unbeknown to Patricia when the doctor telephoned with the scan results, Gilbert was listening in on another phone extension, showing that at this early stage he was aware that something was wrong and wanted to find out for himself what was going on. As Gilbert listened in the Doctor told Patricia that the good news was that he did not have Alzheimer's Disease, however, he did have vascular dementia. When she walked into the room Gilbert was listening in from he announced *'well that's it then'*, and has not talked about his illness or diagnosis since.

Patricia's knowledge of dementia at that time

AC *What did you know about dementia then? Have you had any experience of other people with dementia?*

Patricia described her knowledge of dementia at that time as *'absolutely nothing'*.

Changes in the person and their spousal relationship since the illness

AC *Do you feel Gilbert has changed in any way during his illness? What was your relationship like with Gilbert before his illness? Did your relationship change when he became ill?*

Patricia felt that Gilbert had not changed, personality wise, since the onset of vascular dementia. She described him as *'still easy going'*. However, she acknowledged that there were some inevitable aspects of change.

PW *'No, I mean he hasn't got the intellectual capacity and he was very high in mind. He had a top job.'*

Despite these cognitive changes, important aspects remained constant:

PW *'In other things he still manages a sense of humour, which is quite difficult but, you know, he does. But you know in himself he's the same person'.*

Describing him as the same person reflects, for me, how Patricia views and consequently interacts with Gilbert – as the same person. In other words firstly she still views him as a person and, despite the cognitive changes, sees him as the same person.

In terms of their relationship she acknowledges that there had been a change in roles but, importantly, saw changing roles as an inevitable part of married life:

PW *'oh yes, it's like having another child again. It's exactly like that. Become the mother. But husbands and wives change roles over life anyway'.*

How does the carer see their relative's quality of life?

AC *How would you describe Gilbert's quality of life since his illness?*

Patricia felt that although his physical needs were met, his life must be boring. Here, what I came to think of as Patricia's optimistic slant on life is demonstrated:

PW *'Erm well it's boring for him really. He's reasonably well looked after I think. It's not ideal.....we're lucky in that he's fed and watered and, you know, (laughs) here. It could be infinitely worse'.*

Further evidence for Patricia's view on the quality of life when older and with disabilities was obtained on my final visit when she received a telephone call to say that a neighbour had died. The neighbour had been suffering from Parkinson's disease for some time and was in pain.

Patricia said that although it was sad it was also *'a relief'* as he had no quality of life.

We discussed how Gilbert was much more mobile in the earlier days of his illness. Patricia described those days, showing that she understands that carers and the person with dementia can have conflicting needs.

PW *'Well actually they were much more difficult days for me, but not for him. He would wander. He would just go. And fortunately being in the village, you know, people would just phone and say he's here'.*

It was at this time that Patricia's resourcefulness showed again when she found an electronic 'tracker' which they attached to his belt and they were then able to see where he was within about a mile radius. This illustrates how she viewed it as important to let Gilbert have the freedom to walk around his farm – just as he had done for many years. Some people may have found this too risky (Teresa felt it was). However, it can be seen as an example of Patricia's determination to help Gilbert to still do the activities that he enjoyed, to preserve his personhood.

In recounting some of these stories Patricia showed how humour had been important in coping with these difficulties.

PW *'There was one occasion when he jumped onto the tractor. And he took off with us running pell mell after him!'*

PW *'....I popped into a shop to get something and when I came out he'd disappeared. I was worried in case he'd gone into the woods cos we didn't have the tracker then. Eventually he came out of an office nearby with three lovely ladies who gave him his coat and waved him goodbye – he was chatting them all up for about three quarters of an hour!'*

However, this period of their life also took its toll on Patricia's seemingly unending emotional resources. Gilbert would often try to rearrange the lounge furniture:

PW *'In the evening I'd sit down rather exhausted at the end of the day and he'd walk the chairs all around the room. Totally restless.'*

She also experienced problems during his personal care:

PW *'I couldn't persuade him to sit on the loo. And the sheer frustration of not being able to get someone to sit down on the loo! I was banging my head on the wall in fury! (laughs)'*

The turning point for these difficulties was when Gilbert was prescribed Melleril, which made him very much calmer. However, I suspect this may also have contributed to his sleepiness during the day, as observed in the dementia care mapping.

Communication since the onset of dementia

AC *What has communication been like between you and Gilbert?*

Patricia felt that the paid carer, Ros, was particularly good at communicating with Gilbert in that she asks him to stand up, turn round, lean forward etc during physical care. However, he did not always follow Patricia's requests, and she felt that this was possibly because Ros was a *'professional carer'*. However, in my observations of the couple I noticed how Patricia always talked through physical care tasks when carrying them out with Gilbert, or when moving him in his wheelchair into the car, helping to put him at ease.

In terms of verbal communication Gilbert has limited ability remaining, but Patricia still talks to him, as do the rest of the family.

Recognition

AC *Does Gilbert recognise you and your family?*

Patricia said that Gilbert did still recognise her and family. However, I had experienced a meeting between Gilbert and his grandson, Alex, at the fair, where I felt Gilbert did not show clear signs of recognition.

However I had also witnessed Gilbert recognising (on the same occasion at the fair) an old friend. Patricia said that sometimes he becomes very emotional on meeting old friends.

Does the carer think the person with dementia still knows what's going on? Do they have insight?

AC *Does Gilbert ever have any lucid moments? Do you think Gilbert has any insight into his illness?*

Patricia's view of what Gilbert *'still knew'* was complex. She felt that at times he did understand what was going on but that she could not be sure how much.

PW *'I think he does understand sometimes. Not all the time. Still affectionate, very much so....I suspect there's quite a bit still there'.*

Patricia dealt with this uncertainty by interacting and carrying on as if he did understand. In other words she still treated him as a knowing and feeling person.

PW *'He does understand sometimes. I don't really like to discuss his situation in front of him because I don't really know how much he understands'.*

In terms of his understanding of things around him she felt he still liked to watch television programmes that he used to watch. His reactions to these could also provide her with evidence that he has an understanding at some level:

PW *'If you put on say a war film he'll probably watch it all the way through without falling asleep. It's difficult to know how much he truly understands but he likes to watch it. Sometimes he actually laughs at something that is funny. You know sometimes he understands'.*

What has it been like for the carer?

AC *What has it been like for you caring for Gilbert?*

Patricia became tearful during answering this question. This was the first and only time I had seen her in this way, different from her usual strong appearance. She spoke of how difficult it was but that *'you just have to carry on'.*

Patricia's presentation Feb 2003

When I visited Patricia to do the interview she told me that she had been invited to speak, as a carer of someone with vascular dementia, at a seminar arranged by the Alzheimer's Society. She invited me to go with her. This was a great opportunity to both publicly thank Patricia and Gilbert for allowing me so much time to observe their lives and also to hear Patricia talk about her own experiences as a carer. This would provide further corroborating evidence in the case study analysis and to question whether I had understood what it was like to look after Gilbert from Patricia's perspective.

She spoke of the beginning of his illness and the slow course of its progression. The difficulty of living with someone who was disorientated in time and who became active at night. She also spoke of his early hallucinations where she was perceived to be either Mussolini or Rupert Murdoch. These difficult times have been spoken about by all the carers in this research and are times prior to my visiting. It is possible that future studies should also observe these earlier parts of the illness progression to obtain a fuller picture. In Gilbert's case Melleril was prescribed and Patricia spoke highly of this drug to the astonishment of the audience. In her experience it had calmed his agitation and settled his night waking and activity. However, in my view, it may also have led to his excessive sleepiness during the day.

Patricia also spoke of Gilbert's experience with Aricept (paid for privately). This had raised his Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh 1975) score from 20/30 to 26/30, and he appeared to benefit for about six months. However, after this time the effect wore off and larger doses gave him unacceptable side effects.

She spoke of her infuriation at the social services and lack of help. She also spoke of the great camaraderie and kindness of the local Alzheimer's Society group where Gilbert and she would have lunch. I had seen her as a strong and resourceful woman who pushes away negative thought to 'get on with it' so was surprised to hear her describe publicly her devastation at his diagnosis. Described as more scary to be told dementia than cancer, she felt no-one should have to be alone to hear the diagnosis as she did. However, as I predicted she ended on an upbeat note reminding people that it is vital to keep a sense of humour.

The audience were equally impressed by her resourcefulness, confirming my view of her. She was also surprised by this, not seeing herself in this light.

Summary of findings from visits

Well-being and ill-being profiles

A score of two was awarded, ie 'significant signs' if this type of indicator was felt to be generally present, if there were a number of incidents of this nature recorded. For a score of one the indicator would only be illustrated in a single or very few examples.

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

	Visit 1	Visit 2	Visit 3	Visit 4
Making wishes known	2	1	1	1
Initiating social contact	1	1	1	1
Warmth and affection	2	2	2	1
Self-respect	0	1	1	0
Being helpful	0	0	1	0
Humour	2	2	1	0
Bodily relaxation	2	1	2	1
Creative self-expression	1	2	1	0
Showing pleasure or enjoyment	2	2	1	1
Responding appropriately to others	1	0	1	1
Expressing appropriate emotions	2	2	1	1
Holding their own socially	1	0	1	0
Alertness, responsiveness	2	1	1	1
Being active	1	1	0	0
Being purposeful	1	0	0	1
Total	20	16	15	9

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

	Visit 1	Visit 2	Visit 3	Visit 4
Depression or despair	0	0	0	1
Intense anger	0	0	0	0
Grief	1	0	0	0
Anxiety	1	1	1	1
Fear	0	0	0	0
Boredom	0	1	1	0
Physical discomfort / pain	0	1	0	0
Bodily tension	0	1	1	1
Agitation	0	0	0	0
Apathy and withdrawal	0	0	0	0
Distress	0	0	0	0
Cultural isolation	1	1	1	1
Difficulty withstanding powerful others	0	0	0	0
Total	3	5	4	4

As can be seen from the tables above, the well-being scores decreased over time, whereas the ill-being scores remained consistently low, indicating a continual lack of ill-being. The decline in well-being scores reflects Gilbert's declining ability to communicate and also his declining mobility, both of which have led to a decrease in engagement and inclusion. However the level of ill-being has not increased as a result. Gilbert still appears to be relaxed and content within his surroundings, although he is no longer able to get around on his own; it is difficult even with the help of others. This may be due to Patricia's ingenuity in obtaining equipment to enable him to get out sometimes and also for him to still be included in the family outings and meals. Although the family may talk at a pace which excludes him from joining he seems content to still be part of the gathering.

The Behaviour rating scale for Psychological and Social problems (BPS)

	Cognition/44		Mood/28		Social contact/20		Total/140	
	PW	AC	PW	AC	PW	AC	PW	AC
Visit 1	39	37	1	1	15	9	67	61
Visit 2	40	32	1	0	12	12	71	53
Visit 3	36	37	1	0	14	15	62	69

PW = score as assessed by Patricia Woody
AC = score as assessed by the author

Gilbert's limited cognitive abilities are reflected in his high score from both Patricia and myself. His lack of ill-being is corroborated by the very low scores in the mood category. His reasonably high social contact scores reflect the fact that he does not show much interest in his surroundings and tends to spend quite a large proportion of his time dozing. However he is not showing signs of ill-being here.

The Bristol Activities of Daily Living (BADLS)

	Total score/60	
	PW	AC
Visit 1	52	50
Visit 2	52	53
Visit 3	55	54

PW = score as assessed by Patricia Woody
AC = score as assessed by the author

Gilbert's consistently high scores on the BADLS reflect his continuing dependence on others for his day-to-day living skills.

Dementia Care Mapping (DCM)

The process

One of the first difficulties I encountered in mapping was that it is very difficult to map whilst the carer is engaging the researcher in conversation as well as not being the usual environment for the person with dementia in terms of not having their carer's full attention. Mapping, where possible, was often carried out while I was apparently engaging in other activities such as doing a crossword or reading the paper.

The actual process of recording the data was not too difficult and I found that I could retain approximately 30 minutes of data in my head at any one time. The retention of data was the most difficult and tiring part. By the third day of a three day stay I was becoming very tired and hence mapping periods are often much shorter here.

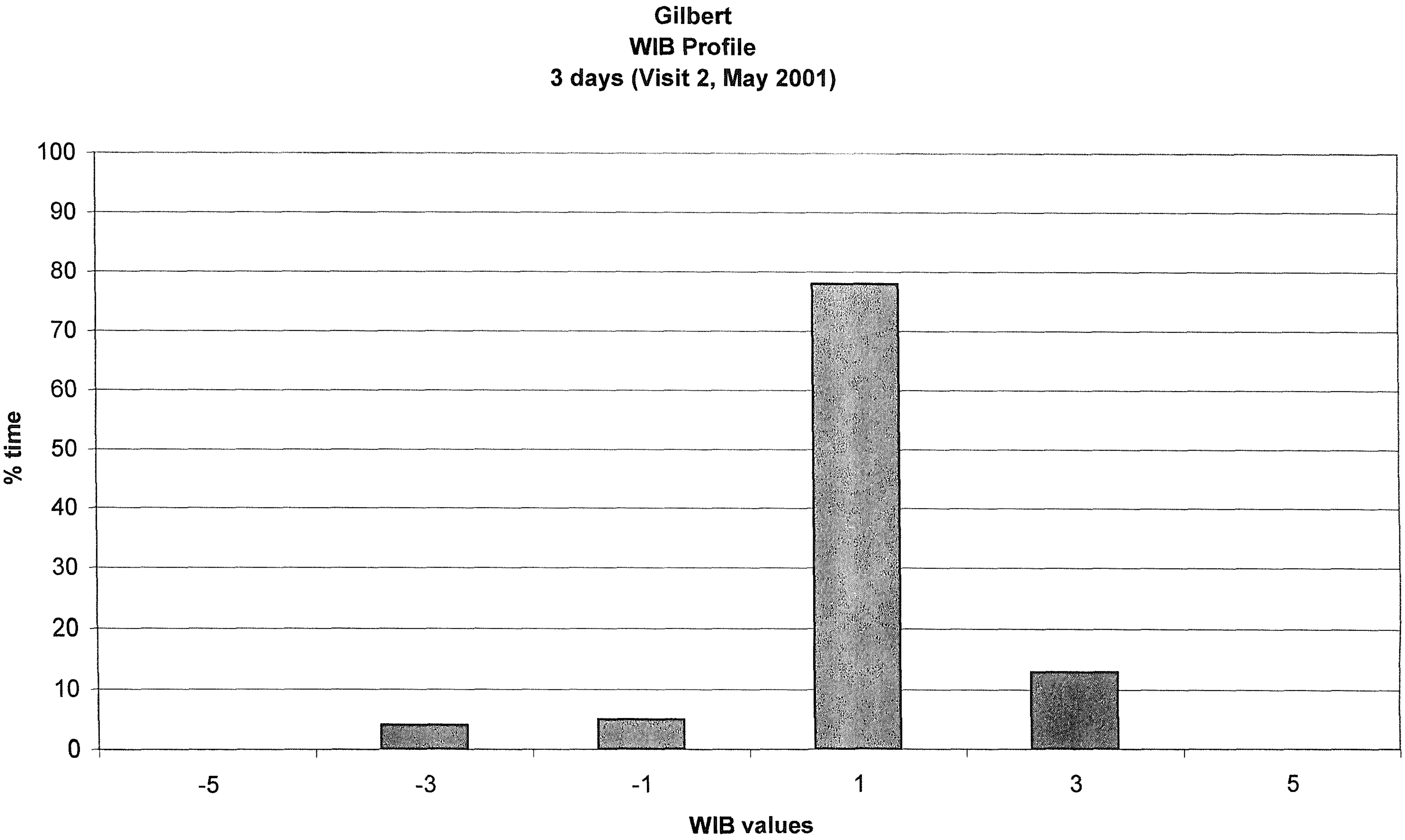
However, mapping was found to be possible during the stays and this opens up the possibility for its use in either other research or perhaps as part of assessment procedures.

The findings

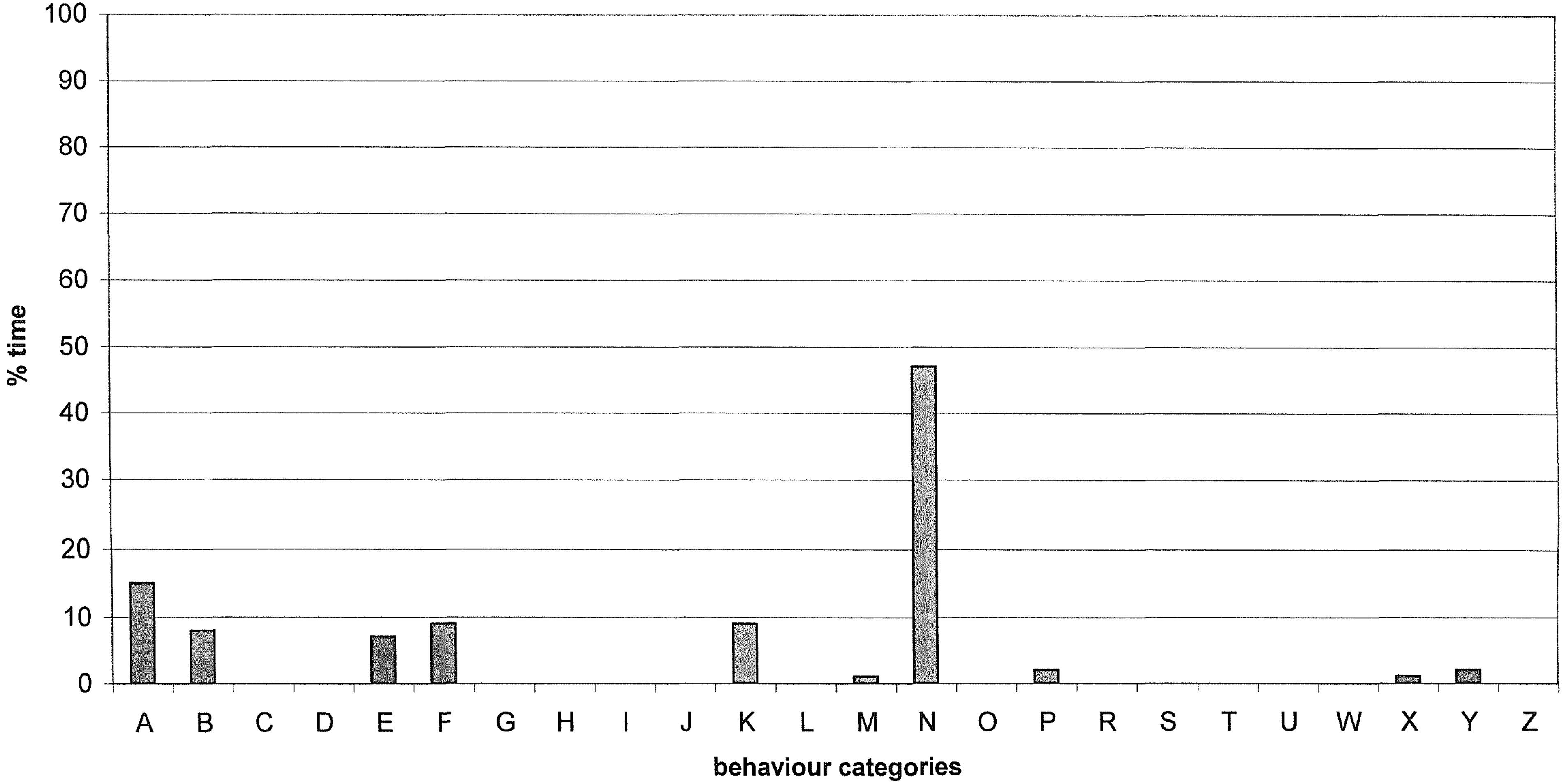
One of the most noticeable aspects of mapping with Gilbert was the amount of sleep he had during the day. Whilst observing this without mapping would have probably led to the conclusion that he spent periods of the day asleep, mapping adds a different dimension to this. In visit two, where DCM was first used, Gilbert slept for approximately half of the total mapping time on each day. When applying the degradation rule for exceeding 'appropriate sleep' during analysis the results are revealing. For DCM in formal settings 'appropriate sleep' is considered as one hour in a day centre and one and a half hours in residential settings. I chose to use one and a half hours in the home setting as most similar in style to the formal residential care setting. This meant that on a few occasions his well-being was subject to the degradation rule and reached –5 at one stage during the third visit. This degradation would only be picked up during an extensive period of mapping. However, it alerted me to the possibility that Gilbert may be bored or over medicated, which I may not have concluded on shorter visits, again highlighting the benefits of an extended period of observation.

What is immediately apparent from the well-being / ill-being profiles of all four visits, presented overleaf, is that the majority of time is spent in a well-being state of +1. Negative values of well-being are almost entirely due to extended sleep periods. Although no +5 moments are recorded, +3 periods sometimes occur during interaction with others and 'creative self expression' which usually consisted of singing or dancing with others. However, the lack of variety in activity was highlighted across the visits by the behaviour profiles presented overleaf. No games, handicrafts or intellectual activities were noted. These types of activity might be present in formal day care settings but music and television were the only activities present in his home. During the second visit I was doing a jigsaw that Patricia had given me and occasionally Gilbert would reach out to touch the pieces, indicating that he had some potential for taking part in games.

Summary WIB profile and behaviour category graphs for the visits are presented overleaf. Day by day graphs for each visit are presented in appendix five.

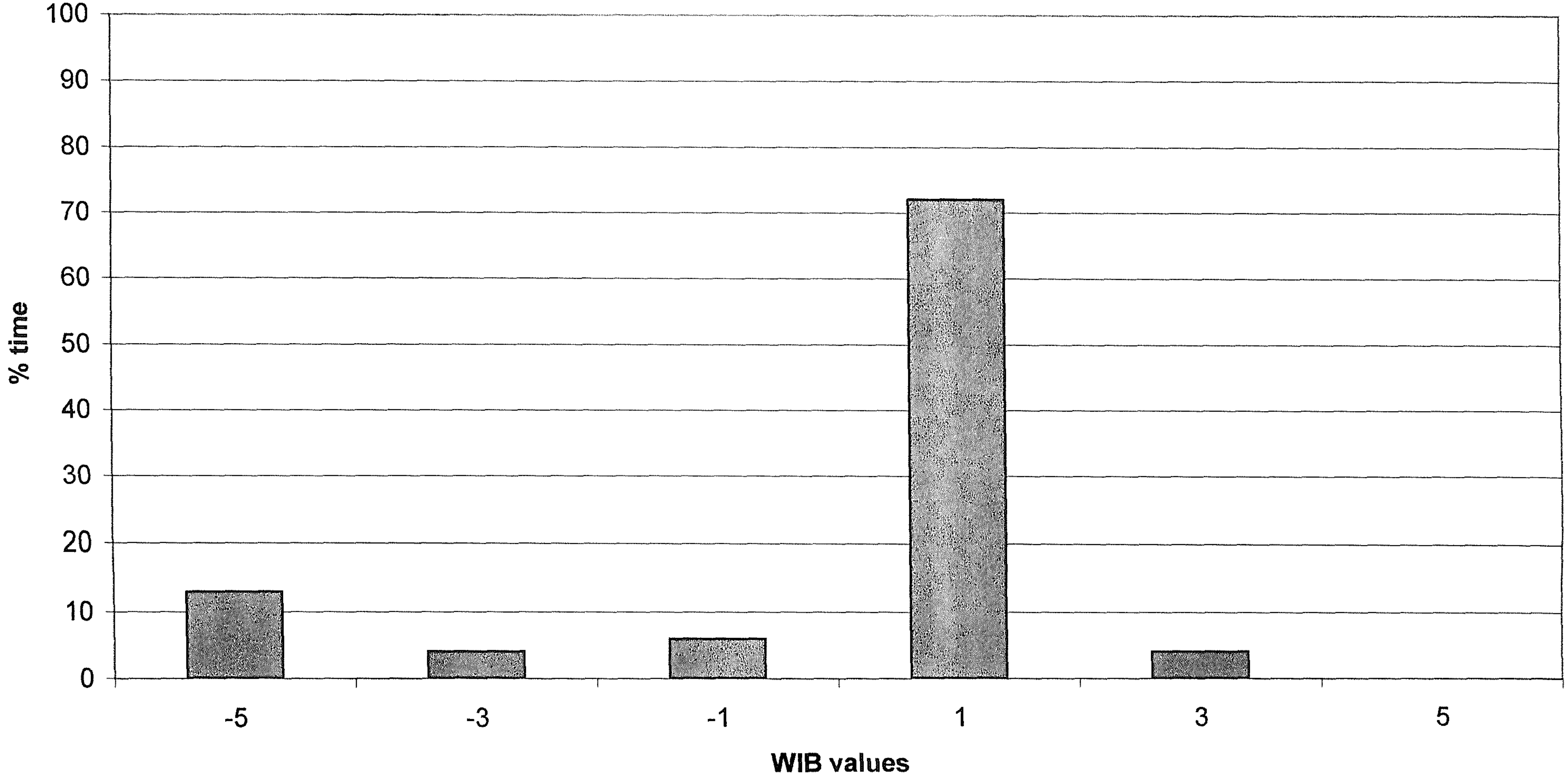


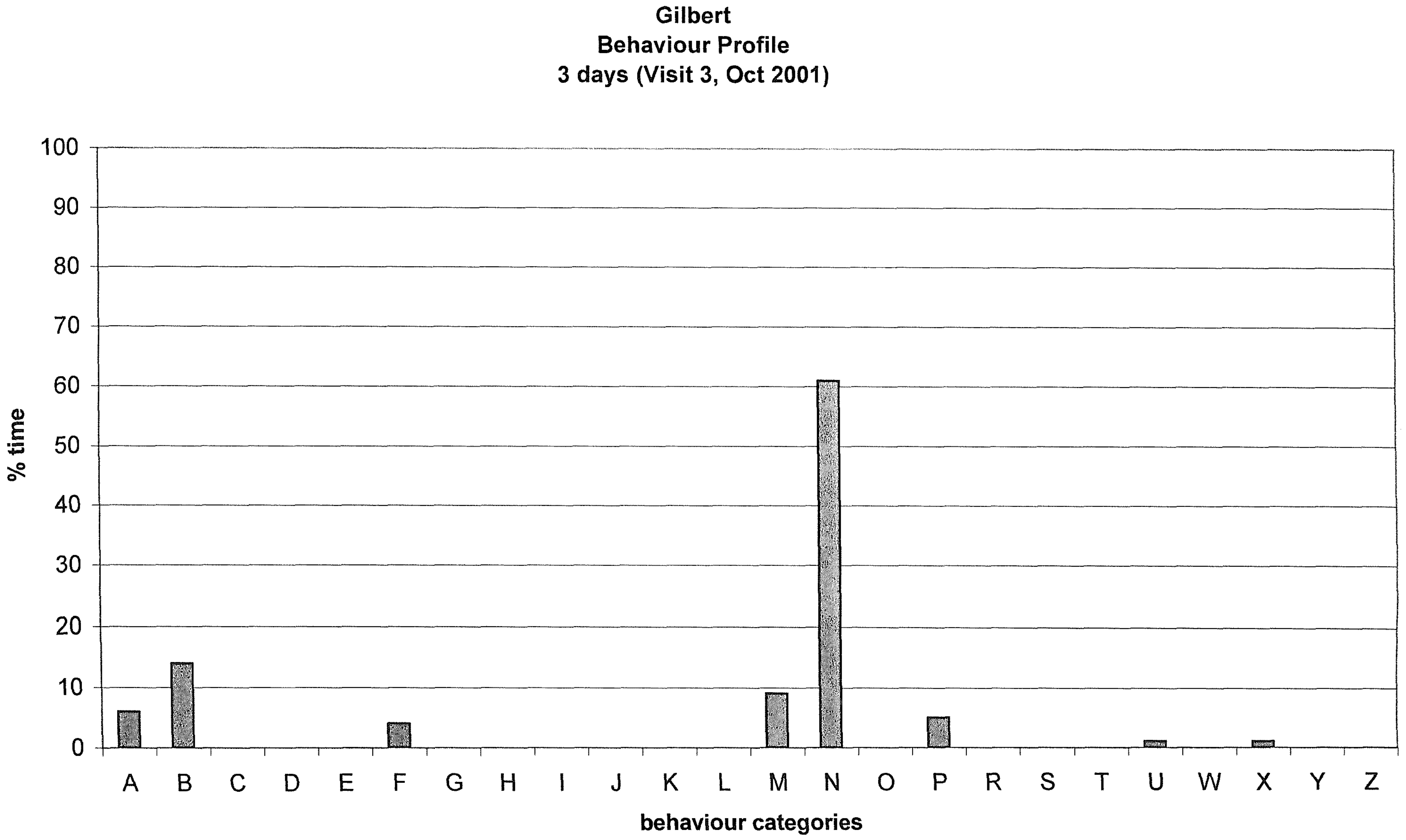
Gilbert
WIB Profile
3 days (Visit 2, May 2001)



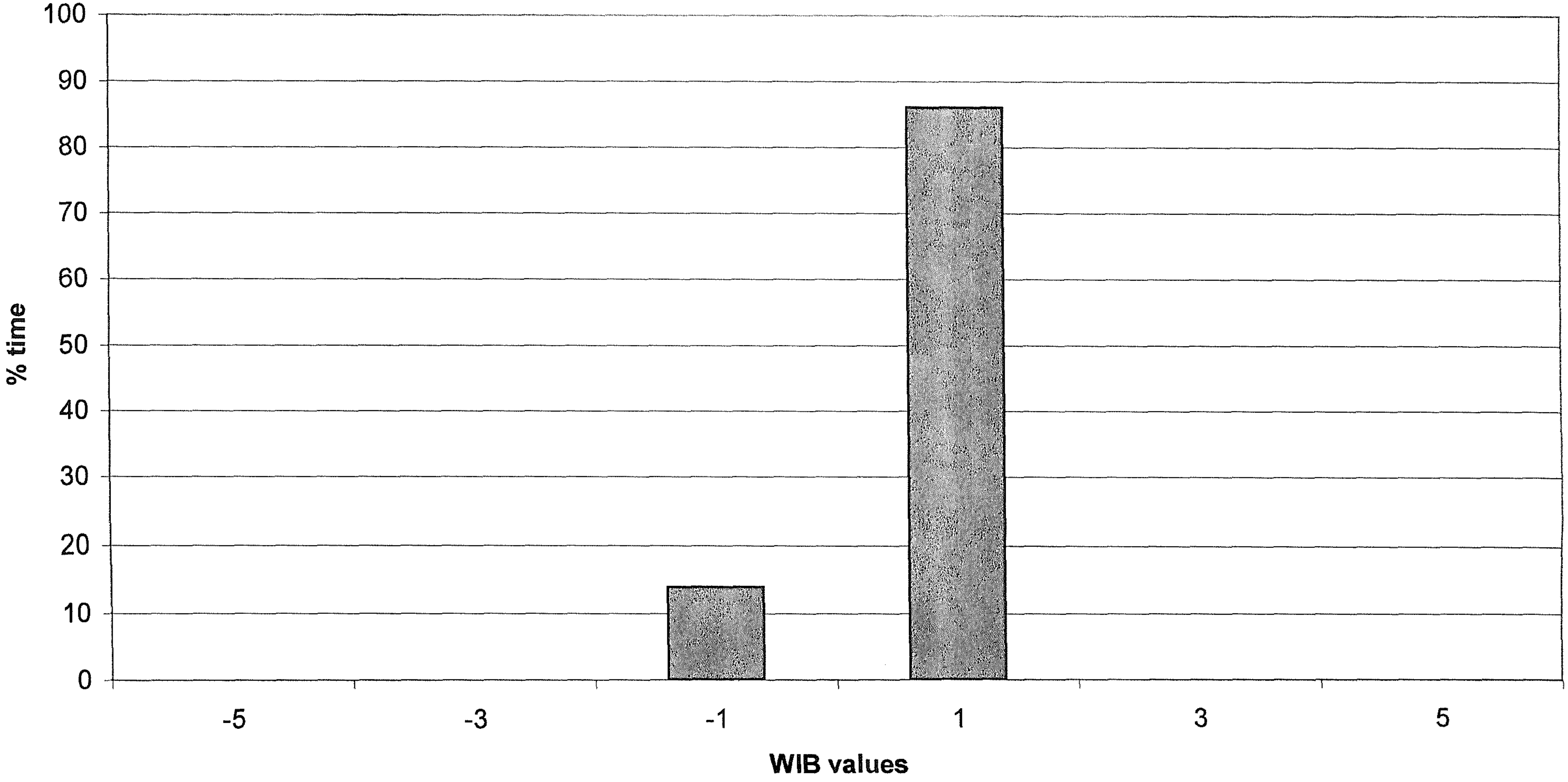
Gilbert
Behaviour Profile
3 days (Visit 2, May 2001)

Gilbert
WIB Profile
3 days (Visit 3, Oct 2001)

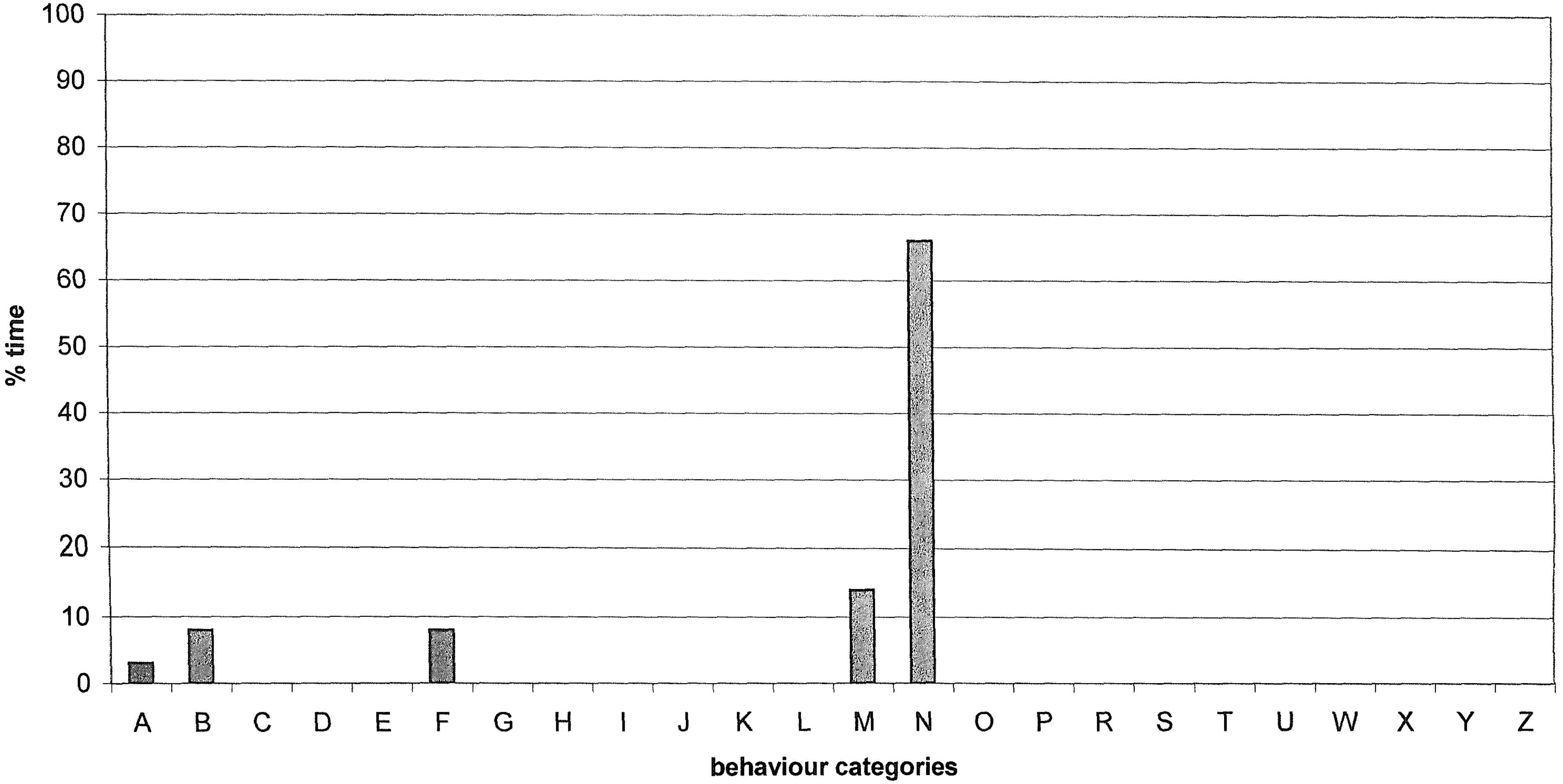



Gilbert
Behaviour Profile
3 days (Visit 3, Oct 2001)
% time
100
90
80
70
60
50
40
30
20
10
0
A
B
C
D
E
F
G
H
I
J
K
L
M
N
O
P
R
S
T
U
W
X
Y
Z
behaviour categories

Gilbert
WIB Profile
(Visit 4, May 2002)



Gilbert
Behaviour Profile
(Visit 4, May 2002)



Malignant Social Psychology and Positive Person Work

In keeping with the results of the ill-being profiles detailed above there were very few instances of malignant social psychology observed throughout my stays with the Woodys. The elements of ignoring, outpacing and banishment were noted on more than one occasion and I feel are to some extent overlapping in their description of the events. In the main they were used to detail instances where Gilbert was physically part of a group but where the pace of conversation rather excluded him, or on the few occasions where he was physically unable to join the group, because of lack of wheelchair access.

Not surprisingly, in accordance with the well-being profiles there were a number of instances of positive person work observed during my stays. Elements of relaxation, recognition, collaboration, facilitation, play, creation, holding and validation were noted, demonstrating the good care which he receives.

Carer support for intact abilities and validation of emotion

The next two categories for observation are taken from (Sabat 2001) and are observed from interactions from the carer to the person with dementia.

Carer support for intact abilities

Two main themes emerged across the course of my visits with respect to this category. Firstly, that Patricia encouraged Gilbert to maintain some activities, where possible, such as wandering around the fields in earlier days of his illness to not strapping him into his wheelchair in latter days. Despite other people feeling that he was at some risk of injury Patricia appeared to put his freedom and support for intact abilities first, increasing his well-being in these areas of his life.

Secondly, the decline in his ability to feed himself was observed over the course of my visits. However, in helping him to eat, Patricia always allowed for his own maximum ability to be used.

Carer validation of emotion

Throughout my visits Patricia shows an acceptance and validation of Gilbert's emotions, both positive and negative. This links closely to her belief that Gilbert has some knowledge of 'what is going on'. Again this highlights the link between good care and a perception of the person with dementia as not yet socially dead.

Politeness strategies and aspects of selfhood

These two important features for observation, as detailed by (Sabat 2001), are aspects of behaviour which are observed directly from the person with dementia.

Politeness strategies

Early on in the visits, despite his failing cognitive powers, Gilbert showed a number of politeness strategies. For example, saying *'after you'* and allowing me to go through the door first. As his mobility declined I was still able to observe his retained politeness, for example, when burping or yawning he would exclaim *'oh excuse me!'* Even when, on my final visit, his speech was extremely limited and he had to rely on others for help with all tasks on daily living, after I had lifted a drink to his mouth he said, *'thank you'*. This retained politeness is seen by (Temple, Sabat, & Kroger 1999) as indicating that important aspects of what makes a person are still intact. For example, in the case of saying *'after you'* to me at a doorway he would have to firstly recognise that we had arrived at a doorway and then remember that it is polite to allow a woman to go through the door first – which would also require him to recognise me as a woman. These aspects of day-to-day interaction would not be highlighted on cognitive tests which are used within the medical sphere.

Aspects of selfhood

In my time staying with the Woody's I managed to see and talk to many of Gilbert's relatives and friends. Gilbert's self as a valued member of his family was still very much intact at the beginning of my visits. At dinner he was seated at the head of the table and was still invited to important family events, for example the opening of his daughter's delicatessen. Other families may have thought his presence at such events too embarrassing or time consuming – but not his family.

However one of his other daughters spoke to me of the loss of self she felt he had suffered in terms of his 'self as engineer'. In his working life he had been able to mend things around the house and on the farm. She said that at one stage she could still get him to mend fences if she took him through the process step-by-step. This was no longer possible and she felt that this aspect of his personality had gone. This example demonstrates how others are vital in helping to keep important aspects of self intact for the person with dementia for as long as possible. Her willingness to do this was amply demonstrated. This shows the strong link between carer support for intact abilities retaining aspects of self for their relative with dementia.

As his mobility declined it became more difficult for Gilbert to get around and enjoy visiting friends, going on outings etc. However, Patricia was resolute in finding ways to get round this. For example, the purchase of the converted van enabled him to travel again when confined to his wheelchair. Where possible he was still included, hence allowing an important part of his self, 'self as social being', to be maintained. This was not always possible as wheelchair access to some neighbour's houses was not always ideal. But where there was access Patricia would take him.

All examples during my stay highlight the important role that carers play in helping to maintain important aspects of self within the person with dementia. In order to perform this I would suggest that the carer does not believe that their relative is socially dead.

Perception and social death

As mentioned above, the willingness of Patricia to help maintain, where possible, important aspects of his self demonstrates to me that she did not believe that he had ‘ceased to be there’ (i.e. social death) once his cognitive deficits had restricted conventional communication. This view is corroborated by the interview with Patricia, detailed on page 120.

Longitudinal profile

Gilbert’s mobility declined over the course of the study. Whilst he was initially able to walk unaided, by the time of my final visit he required the use of a wheelchair and hoist on a full-time basis. At the time of my first visit Gilbert had limited speech remaining. During the course of the study his engagement with others decreased. This was reflected in a very slight decrease in well-being but, importantly, not an accompanying increase in ill-being. In other words it could be suggested that his disengagement was as a result of the dementia rather than the nature of any interactions – the best Kitwood would hope for. As mentioned previously, his decline in ability was offset to a great extent by the ingenuity of Patricia. Their relationship remained strong throughout, as she continued to treat him with dignity and respect as she always had.

Résumé

Gilbert's declining abilities, in terms of self care such as feeding and dressing, and mobility, were observed over the course of the visits. His well-being remained generally at a good level but dementia care mapping highlighted some periods of excessive sleep which could be due to under stimulation, boredom or overmedication. However, his family still very much include him in the day to day activities, such as mealtime gatherings, which help to retain his personhood. Patricia, in particular, treats Gilbert with great respect and kindness showing no belief in social death and no associated behaviour.

A key aspect in my view, in retaining his personhood and well-being, was Patricia's help in maintaining Gilbert's independence and lifestyle where possible. The 'tracker' allowing him to walk around his farm is one example. Here the balance between independence and safety is seen. Gilbert may have been at less risk of a fall sitting in his chair at home, watched by a carer, but his well-being would have been compromised.

Mr and Mrs Dudley

Background

Claire and Neil Dudley had worked together as a team since their marriage 43 years ago. Once keen sailors, people spoke of how when they crewed a yacht they worked together as one, communicating without words. Ironically their team work proved useful when Neil developed frontal lobe dementia. Claire's calm yet encouraging manner, talking him step by step through tasks such as dressing, enabled Neil to use some of his intact abilities, although words were limited.

Neil, a retired engineer dedicated to his science from researching his doctorate to retirement day, was 68 when I first met him. The Dudleys lived in Bedford, having moved nearer to their son and daughter in law and two grandchildren. I first met Claire at the coffee morning arranged by the day centre to help with my recruitment of participants. Although willing to take part she was keen to point out that they *'didn't do much'*, and voiced her concern that Neil would not survive the planned length of my study.

It was just after Neil's retirement that the initial signs of illness became apparent. Once a safety conscious motorist Neil turned into what Claire described as a *'fiendish driver!'* As well as taking risks he also seemed to become disorientated at times. Claire put this down to the onset of old age, being newly retired and the ensuing change of pattern in day-to-day routine. She spoke of noticing behavioural rather than memory changes. His friends also noticed this change during a regular golfing trip and expressed their concerns to Claire. Worrying that he wouldn't agree to go to his GP she told him that the GP wanted to see all newly retired people for a check up. It was here and at subsequent consultations and scans that she learned that he had frontal lobe dementia. Neil never mentioned his illness, appearing accepting of it, which puzzled Claire as his training had taught him to question everything.

A previously romantic man, who would always buy red roses on birthdays and valentines day, Claire noticed that he had missed her birthday and subsequently showed no interest in celebrating their 40th wedding anniversary. She spoke of this change from the man she married as being hard for her, that sometimes she felt he wasn't her husband but a stranger. She also didn't seem to feel that he was aware of his illness, speaking of caring for him as *'like caring for no more than a cat'* when interviewed after his death. However I did not observe her feelings about Neil being a stranger being translated into behaviour when caring for him. A gentle woman, Claire always treated Neil 'as if' he knew what was happening to him. She would feel guilty if she wasn't providing stimulation during the day for the once so mentally brilliant man.

Although she spoke of the difficulties of their situation she was adamant that it was not all negative. She spoke of the extreme kindness she had witnessed from other people in a similar situation, from nurses and carers, and from the friends she made at the local Alzheimer's society group. *'If this hadn't have happened I would never have met these lovely people'.*

With the help of private medical insurance Neil tried Aricept and Exelon for short periods during his illness, neither showing any effect. Remaining positive Claire felt that you didn't know what decline in ability might have happened if he hadn't tried the medication.

His mobility had decreased in the last year of his life following a deep vein thrombosis in his leg. This meant that he required assistance to move around, in his latter days by wheelchair. However, he seemed content to sit in a chair for long periods of time, never seeming to become frustrated or to try and move himself.

I visited them twice for lengthy observation, although Claire did not feel I needed to stay overnight as Neil always slept well. So I returned home at the end of each day. I felt to some extent that this prevented the closeness I had felt towards other couples. However, it also allowed me to switch off at the end of each day. Neil spent two days at the day centre I was familiar with, Homemead, and a third at a local residential home. Claire hoped that these venues would provide the mental stimulation that she was not always able to give him. I was able to observe him in both day centres and also on some of the Christmas outings arranged by Homemead.

Neil died shortly after my second visit, having taken a turn for the worse and been admitted to residential care.

Visit 1, September 2001

When I first arrived at the Dudley's Neil was still asleep. His bed was in one part of the lounge – not an ideal solution according to Claire, but soon to be resolved as they were going to swap houses with their son and daughter-in-law who lived nearby. Their new house would be smaller, but of a better lay out for Neil, considering his mobility problems.

Claire woke Neil and helped him to prepare for his day at the day centre. I was immediately impressed by the teamwork between them in getting Neil washed and dressed. Claire's gentle prompting and Neil happy to help. Her manner enabled him to carry out self care tasks such as shaving, brushing his teeth and dressing, but required her help in prompting throughout.

We drove to the day centre, and I noted that Neil does not appear to mind going, he showed no resistance and was happy to be greeted by the care staff. As I was already familiar with the staff I felt at home and settled into the day observing. I was also pleased to see that two of my other participants, Anne Reed and Monty Archer, were also present, which meant that I would be able to make additional observations on them too.

The day progressed as usual at the centre, beginning with some reality orientation in terms of the day, month and weather etc. This was followed by a short quiz, and I noted that Neil was not asked any of the questions, presumably because of his difficulties with speech. One or two of the more able clients were also keen to call out the answers.

Neil did join in the gentle exercising to music and then with the handicraft activity. Here he spent some time carefully cutting out shapes that I had drawn, despite having difficulty in applying any pressure to the scissors with his hand.

After lunch he took part in a game of beetle drive using a large dice. Although he seemed content to take part in activities and did not show any signs of ill-being he only occasionally lifted to a WIB score of +3, mainly staying at +1.

As I had spent much of the day with Neil at the day centre I didn't feel I had 'bonded' with Claire as much as I had done with other carers at this stage of my visit. This was also to be compounded by not staying over night, as Claire did not wish me to since Neil always slept soundly. However, we had a good evening watching the England vs Albania football match on television. Neil was clearly watching and understanding the game as he cheered both times that England scored.

I realised that I was very tired after my day at Homemead as I dropped off to sleep briefly during the 6 o'clock news on television. I was glad to be going home to my own bed where I could be 'off duty' as an observer for a few hours. However, I still had to dictate my notes from the day into the tape recorder before turning in for the night.

The second day was spent at the Dudley's home and I felt I got to know Claire much better and felt more comfortable in her presence. I arrived before Neil had got up, but this was mainly because the nurse had not arrived. Unfortunately she didn't turn up and Claire got Neil up on her own, seeming unphased by this occurrence.

Most of the morning was spent listening to Classic FM and reading the newspaper. It was a quiet morning compared to the day centre. After lunch Claire and Neil had a short nap and I sat listening to the grandfather clock ticking away our lives.

We later drove to the local hospital as Neil had to have a blood test to check his warfarin levels. Claire took a long route home to show me round the town. Although I felt she was doing this to 'entertain the researcher' she said that she liked to drive around sometimes as she felt it gave Neil more stimulation. She felt that she did not provide the kind of stimulation that he got at the day centre and said she felt guilty about this. Neil seemed to enjoy the ride and pointed out the bus station en route home.

For me, one of the most memorable aspect of the day was the meal in the evening. I had told Claire that I was a vegetarian and that I would bring some of my own food so as not to cause any extra cooking but she had replied that her and Neil were also almost vegetarian and that this wouldn't be a problem. On the first day we had beautifully roasted peppers. However, unfortunately on the second day Claire prepared a chicken dish. I felt that I couldn't possibly say anything as I was a guest in their home and decided that this was one of the hazards of participant observation. Having not eaten meat for over 15 years I was concerned that my stomach might react badly, especially as Claire had given me an enormous portion (as I was a student!). Although it lay heavy on my stomach there were no ill effects. Apologies to the chicken.

The final day saw the same pattern of getting Neil up and dressed and preparing him for his day at the residential home. Neil had been going there once a week for the past two years and seemed to enjoy the day. One of the carers noted that he used to talk about his work days but since his speech had deteriorated this was no longer possible. The activities were more sedate than at the day centre; before lunch we read magazines and some of the residents chatted to the staff.

Lunch was another interesting event from my point of view as it was chicken. Again I felt I must eat it as I didn't want the staff to tell Claire in case it caused her any embarrassment. Again apologies to that chicken.

The afternoon began with a nap and then ended with games of dominoes. Here I was able to observe Neil choosing the correct domino and showing that he could still count as he ran through how many dominoes he had left at one point. However, he was not always able to decide when it was his turn and needed prompting.

Day trip from Homemead – Christmas shopping and Harry Ramsden – December 2001

Every year the staff from Homemead would arrange a Christmas shopping trip followed by a meal and entertainment. I often helped out with these trips as a way of thanking then for their help in finding participants for my study. In addition it allowed me to make further observations. On this particular outing Monty Archer and Neil were present.

I was assigned to help Neil in finding a present for Claire. We borrowed a wheel chair from Marks and Spencers and set off with some of the others to have a look round. Although I talked to him throughout the search for a present I found it very difficult to keep the conversation up because he did not reply. However, he found some musical socks and was delighted when I pressed the button. After a couple of hours looking round the shops we moved on to the local Harry Ramsden's for a fish and chip dinner with entertainment. By then I was feeling exhausted and a number of the older people from the day centre also looked tired. However, Neil did not show any signs of fatigue. He joined in the singing of carols, clearly enjoying himself, and ate all of his fish and chips.

The event must have been tiring for most of the older people, as it was quite a long day. Even Neil fell asleep whilst waiting for the minibus driver to turn up at the end.

Visit 2, February 2002

This was a two day visit as I was now working part time, so fitting in three day visits was very difficult.

On arriving I spotted a large vegetarian cookery book. Following last visit's dietary difficulties my hopes were raised only to be quickly dashed when Claire put the book away telling me that her sister had visited and was a vegetarian and how she was glad that I wasn't. I awaited the evening meal with trepidation.

The first morning I sat with Claire and Neil as she updated me on events from the past six months. She was keen to talk but afterwards went over to Neil and cuddled him, apologising for ignoring him whilst chatting to me. This highlights one of the limitations of participant observation in that the observer is necessarily altering the dynamics to a certain extent. However, I felt that this was just while I was being updated on progress and we exchanged news – just as you would with any visitor or friend, and was an important part of us all settling into the stay.

One of their main pieces of news was that they were now living in their son and daughter-in-laws old house, having swapped houses recently.

This made living arrangements a little easier as Neil was able to have a private bedroom on the ground floor rather than sleeping in the lounge. This also changed my observation of personal care as Claire left the room with Neil to his bedroom for these tasks, whereas before I had been in the same room but turned away for privacy.

Although I did not initially notice any change in Neil's condition, it later became apparent that his mobility had declined and also his ability to carry out own care tasks, such as brushing his teeth. I did not observe the latter change in his ability on the first day as I had arrived after he had got up and dressed. However on the second day, when I arrived earlier, this was observed. This again highlights one of the advantages of longer periods of observation.

The first day of my visit was spent quietly at the Dudley's own home. The previous week Neil had been on respite at Homemead whilst Claire spent some much needed time relaxing with her sister. At lunch Claire pointed out that Neil was waiting for her to feed him, and she felt this was a *'lazy'* habit which had arisen during his week away. With gentle prompting he fed himself. After lunch Neil sat wiping his plate with small, repetitive movements before being helped to his chair. Neil and Claire then had an afternoon nap whilst I sat trying to stay awake by doing a puzzle. My head kept nodding asleep.

Spending most of the day in his chair, Neil rarely moved out of a WIB score of +1, never showing any signs of discomfort or anxiety. However, when one of his favourite television programmes, Countdown, came on he sung along to the theme tune and smiled.

I watched television with Neil whilst Claire prepared the evening meal of sausages. I managed to eat them but they laid heavily on my stomach. I also developed a dull but irritating headache which I later discovered was due to caffeine withdrawal when I noticed that even the Dudley's tea was decaffeinated. Fortunately as I was not staying the night I was able to top up my caffeine levels at home, and also to bring some 'pro-plus' caffeine tablets with me for day two.

The second day was spent at the day centre, but I arrived earlier enough at the Dudley's to see that Claire now had to clean Neil's teeth for him – using an electric toothbrush, a change from before. On arriving Claire asked me to stick my head round Neil's bedroom door and say *'hello'*. To my surprise he replied *'hello'*, a word I haven't heard him say before, much to Claire's delight.

On arriving at Homemead Claire used a wheelchair to help Neil from the car to the day centre room, another decline in his abilities from the previous visit. Interestingly at the day centre he didn't use a frame to help move to the table where we were doing handicrafts, but still required assistance. He fell asleep during part of the exercises but when he woke up he followed the remainder of the heel and toes movements. He also seemed willing to take part in the handicraft activity where we were making daffodils and spent much time cutting out the centres which were formed by making a fringe. When I mentioned this to Claire later she said that he still appeared to be good at coordination with *'small fiddly things'*.

Unfortunately I was not able to do any mapping at Homemead as they were short staffed and pleased for me to help out. However, this did mean that I spent some time talking to another of my participants, Anne Reed, who was now a resident following her knee operation (see her case study for details).

After lunch we played horse racing which involved throwing a large dice on the floor to decide on progress up the field. Neil was able to do this with prompting and won twice! Claire came to pick us up and he recognised her as soon as she walked through the door. We returned to the Dudley's home for a cup of tea before I left to drive home.

Claire's interview – November 2002

Claire was willing to do the interview despite Neil's death earlier in the year. She often used the term *'we'* in the present tense, even though there is now only her. An example of social death not occurring even after biological death.

When I left Claire's I tried out the tape and found that her voice had come out very faintly so I made some extra notes in case I was not able to transcribe the whole tape.

How it began

AC *Can you remind me what actually happened? (i.e. with Neil's illness)*

Claire had noticed that Neil's driving had changed from being very safe to quite erratic and risky. He would also sometimes become disorientated whilst out driving. She said she put this down to the fact that that he had just retired, to old age, just being together and not the same pattern of things happening on a day to day basis.

However, one event in particular made her actually book up an appointment for the GP. He had gone away with friends on a golfing trip and they phoned to say something wasn't quite right and advised her to get him to see a doctor.

AC *So did you go to the GP first?*

CD *'Yes, well I thought about it for a few days and I rung my son as well and we discussed it'.* Claire thought it would be a problem to get Neil to go down to the doctors so she told him that the doctor wanted to see everyone that had been newly retired for a check up. And it went from there.

AC *Did he get a diagnosis?*

CD *'Nobody ever said to me, I think he went off for a scan and things, erm no body ever actually looked me in the eye and said he's got Alzheimer's or whatever. But it was actually frontal lobe. He went for a second scan. But they pussy foot around with these things. I never wanted to hide it from him, I just didn't want him to worry. But he didn't even blink at the mention of the word 'Alzheimer's', I mean if I said 'shall we go to the Alzheimer's lunch?' or something.'*

Claire's knowledge of dementia at that time

AC *What did you know about dementia then? Had you known anyone with dementia?*

CD *'Yes well I had been involved in setting up a day centre some time ago in Brookfield, before I came down here. And they had various clients – two dementia patients who had to have special sessions. And I remember saying something about Alzheimer's to someone and they said oh no he's got something else and that was the first time I realised that there was more than one type of dementia.'*

Changes in the person and their spousal relationship since the illness

AC *And when Neil became ill did you feel he changed in any way as a person?*

CD *'Oh yes. His driving became strange – he was disorientated and turned into a fiendish racing driver! He had to be there first. He'd* *always been a good driver – a fast driver – but he was very aware of safety. He wouldn't think anything of a bend!'*

AC *And did your relationship change?*

CD *'Oh yes. Because you become their mother and their carer. The man you married isn't the same at all. I mean you do change over the years but he used to be a very romantic man – birthday, valentines day you would always get red roses or things and suddenly I was aware that I had had a birthday with no cards – you know nothing at all. And that wasn't like him at all – not the man I knew. And for our 40th wedding anniversary she had wanted to do something, let's go out, let's go away somewhere special and he was at first but not later'.*

Claire went on to speak about how Neil lost interest in many things, which was particularly surprising as he had been such a clever man.

How does the carer see their relative's quality of life?

AC *And how would you describe his quality of life? During his illness.*

Claire spoke of the change in enjoyment for Neil. *'For example at Xmas he used to be almost child-like. He would pile up the presents to see if he could get them to reach the ceiling. He lost all interest. For two Christmases he had no interest in presents. The last year was very miserable for him. About 12 months before he died he had that DVT'.*

Communication since the onset of dementia

AC *What was communication like generally between you two, because I do remember he had very limited speech. How did you get round that?*

CD *'By knowing his habits over the years. I was making all the decisions for him.'*

AC *I remember watching you two – you were helping him get undressed and it all worked remarkably well, very smoothly, as though you both did work well together.*

CD *'Well, going way way back when we first knew each other we used to sail together and he was an incredibly good sailor – Olympic short list team that sort of thing. And when we were sailing we would know exactly what to do without telling each other. We used to work well!'*

Recognition

Neil clearly recognised Claire – I had witnessed this on many occasions, for example when she picked him up from the day centre.

AC *Did Neil recognise the family?*

CD *'I think he recognised the children, although some of the new ones he didn't – but he was always pleased to see them'.*

Does the carer think the person with dementia still knows what's going on? Do they have insight?

AC *Did Neil have any lucid moments?*

CD *Very very rare. At one point he stopped talking very much and he just said yes. So I used to ask if he wanted tea or coffee so he had to decide. Everything was yes, and when I got used to it I would work around it. It was a bit of a problem in the hospital because the junior houseman would say 'does it hurt there?' and he would say* *'yes'. He had every disease in the book! And I had to say phrase it other ways. We got there though.*

Then Claire went on to describe an incident at the end of his life which, for her, showed that there was something *'still there'*:

CD *'And right at the very end the last week, he was in hospital. And this nurse who was very blonde, barmaid sort of rushed in and said 'come on Neil I'll give you a kiss and you can give me a smile'. And he looked at her and said 'NO!' this reduced me to hysterics. Something there'.*

In contrast with this final event generally Claire seemed to feel that Neil was not aware of what was going on but this did not come across in her care.

CD *'The last twelve months, I don't think he was aware. He wasn't frustrated, he accepted everything'.*

She went on to describe how looking after someone in Neil's condition was like looking after *'no more than a cat'.*

This feeling that Neil was to some extent not a person anymore also came across when she spoke of how caring for someone like Neil helped you to prepare for being on your own after their death

CD *'because you've been on your own for so long'.*

AC *And when you said you didn't think that Neil had a lot of insight later on. Did he have any at the beginning at all? Did you ever speak about it?*

CD *'We never spoke about it. I remember trying to talk about it saying I hope the diagnosis is good and I remember thinking what we might* *do depending on what she says, but no. I don't think until right at the end he thought there was anything wrong with him. He just accepted it. Because of his training he used to question everything and suddenly nothing at all'.*

AC *What was it like for you while you were looking after Neil?*

CD *'Oh that's the hardest question of all. You do it, of course you do, you look after them as you would a child, you accept it you do it. But sometimes you look at them and think that's not my husband this is a stranger. But everyone was incredibly kind'.*

Claire went on to describe how kind all the people she met through the Alzheimer's society and at the day centre.

Summary of findings from visits

Well-being and ill-being profiles:

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

	Visit 1	Visit 2
Making wishes known	0	0
Initiating social contact	1	1
Warmth and affection	1	1
Self-respect	0	0
Being helpful	2	2
Humour	0	0
Bodily relaxation	1	1
Creative self-expression	1	1
Showing pleasure or enjoyment	1	1
Responding appropriately to others	1	1
Expressing appropriate emotions	1	1
Holding their own socially	0	0
Alertness, responsiveness	1	1
Being active	1	1
Being purposeful	0	0
Total	11	11

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

	Visit 1	Visit 2
Depression or despair	0	0
Intense anger	0	0
Grief	0	0
Anxiety	0	0
Fear	0	0
Boredom	0	0
Physical discomfort / pain	0	0
Bodily tension	0	0
Agitation	0	0
Apathy and withdrawal	1	1
Distress	0	0
Cultural isolation	1	1
Difficulty withstanding powerful others	0	0
Total	2	2

The visits, six months apart, showed no change in well or ill-being indicators. Although Neil did not have a very high score for well-being, this is counterbalanced by an equally low score in ill-being or a lack of ill-being. This may be because Neil rarely showed emotion of either positive or negative feelings. He was extremely helpful in terms of moving his limbs or putting on clothing when prompted to do so by Claire. This formed the basis for their teamwork with caring – she would ask him to help her by moving or pushing or raising limbs etc. There were instances of enjoyment – some of a high level – which will be discussed later in the case study.

For ill-being, Neil showed some signs of apathy at the day centre when games using verbal expression, such as quizzes, were played. However, he joined in when the games involved gentle physical movement, such as rolling a dice. Being younger than most of the day centre clients, and also with a high pre-morbid level of intelligence, I felt that Neil suffered some cultural isolation. However this is my interpretation, not Neil's.

The Behaviour rating scale for Psychological and Social problems (BPS)

	Cognition/24		Mood/20		Social contact/12		Total/100	
	CD	AC	CD	AC	CD	AC	CD	AC
Visit 1	19	13	0	1	12	8	46	30
Visit 2	20	12	0	0	12	9	45	33

CD = score as assessed by Claire Dudley
AC = score as assessed by the author

Claire didn't not give a score for questions 8, 11, 16, 17, 18, 20, 25, 27, 28 or 30, so these were omitted from the author's final scores also.

The scores made by Claire and I show good agreement on the mood category. Neil's lack of negative mood states is also verified on the well-being and ill-being indicators, showing agreement here.

There is a difference between scores on cognition and social interaction suggesting that I viewed his cognition as less impaired than Claire did. The difference in social contact scores also suggests that I felt he had more capacity for social contact than Claire did. This may be because Claire did not observe him during his time at the day centres.

The difference between visits is only observed in my score for cognition. Here I was reflecting the change in Neil's ability to carry out self care, such as brushing his teeth.

The Bristol Activities of Daily Living (BADLS)

	Total score/60	
	CD	AC
Visit 1	41	42
Visit 2	37	44

CD = score as assessed by Claire Dudley
AC = score as assessed by the author

The scores for activities of daily living show greater agreement here between Claire and I. This perhaps suggests that our difference in cognitive scores on the BPS would reflect activities outside of the types of skills measured here.

Dementia Care Mapping

Since Neil was a quiet man who spent large periods of his time sitting in a chair it was relatively easy to map for long periods, using a puzzle book to write down codes whilst not disturbing any of the people present.

On the first visit, which was over three days, I managed to map Neil at home and in both day care settings for a total of 14 hours. During this mapping time his WIB score was mainly +1, with occasional +3 events. There were no negative WIB values scored.

In terms of activities, Neil spent a third of the total mapping time on the first visit watching television. This was not always a passive activity however, as he reacted on a number of occasions to events taking place on the television. For example, during the England vs Albania football match he cheered both times when England scored.

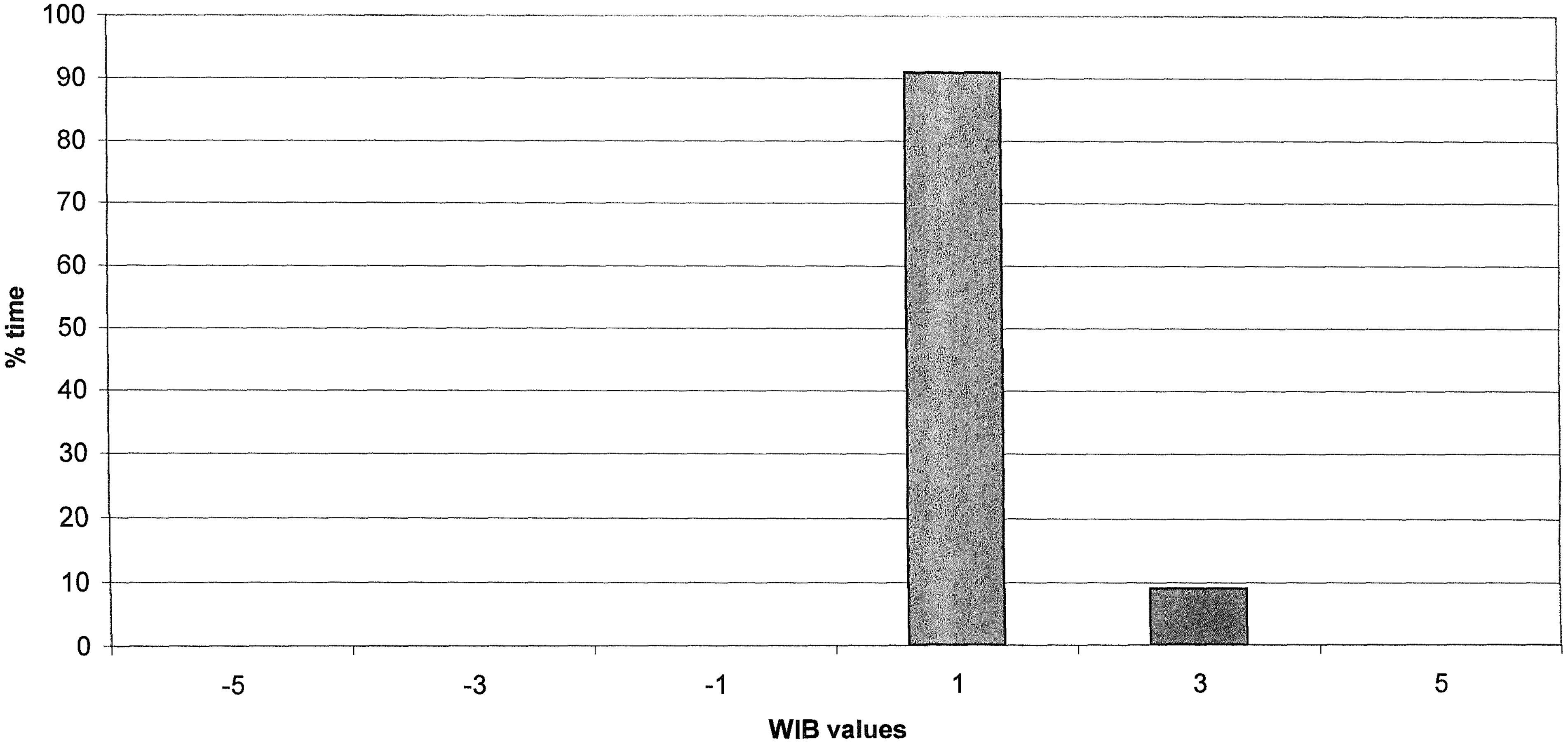
The behaviour profile for the three day visit shows that Neil carried out a range of activities, importantly including a variety of type one activities, which involve active interaction and are thought to be important in maintaining well-being.

During my second visit to the Dudleys I managed to carry out four hours of mapping on the first day, when we stayed in their own home. The second day was spent at Homemead but I was unable to map here as there was a staff shortage and I was helping out.

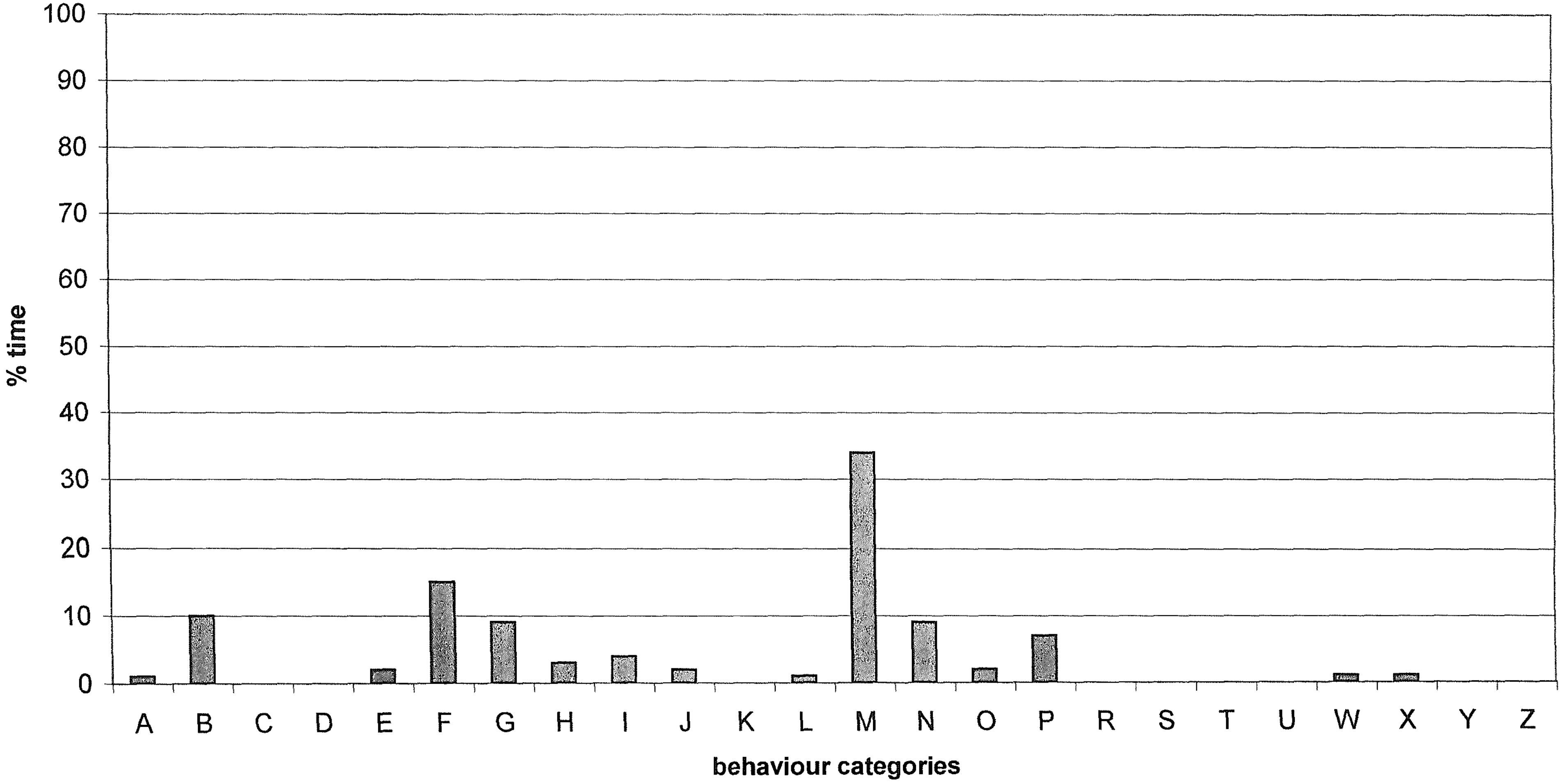
The WIB profile shows a similar pattern to the previous visit, with most scores being +1 and occasional +3 moments. Over half of the total mapping time was spent watching television, and as before this was not just a passive activity, with Neil singing along to the theme tunes of Countdown and Eastenders, clearly enjoying himself. He also spent 20% of the mapping time asleep, perhaps an indication of his decline.

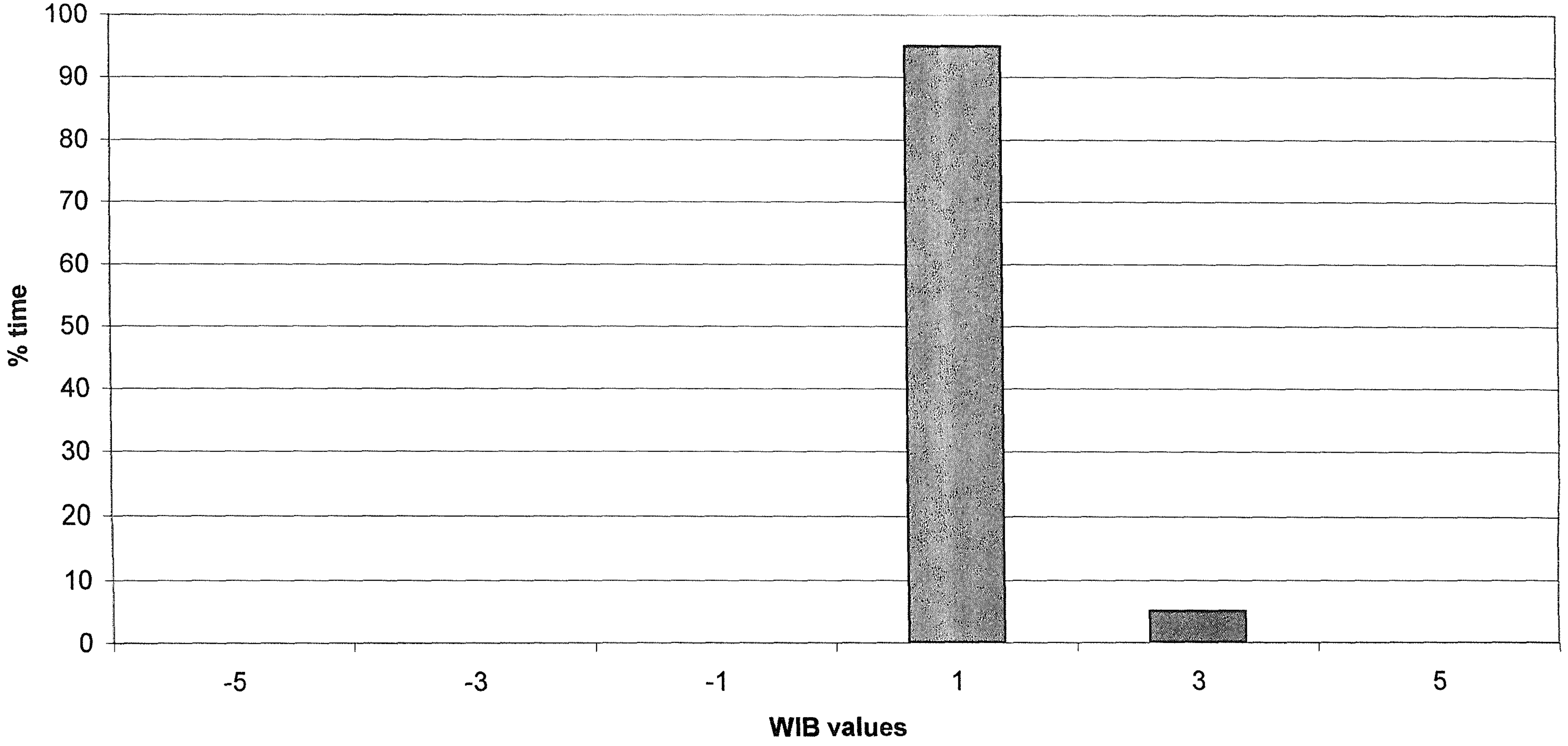
Summary WIB profile and behaviour category graphs for the visits are presented overleaf. Day by day graphs for each visit are presented in appendix six.

Neil
WIB Profile
3 days (Visit 1, Sept 2001)



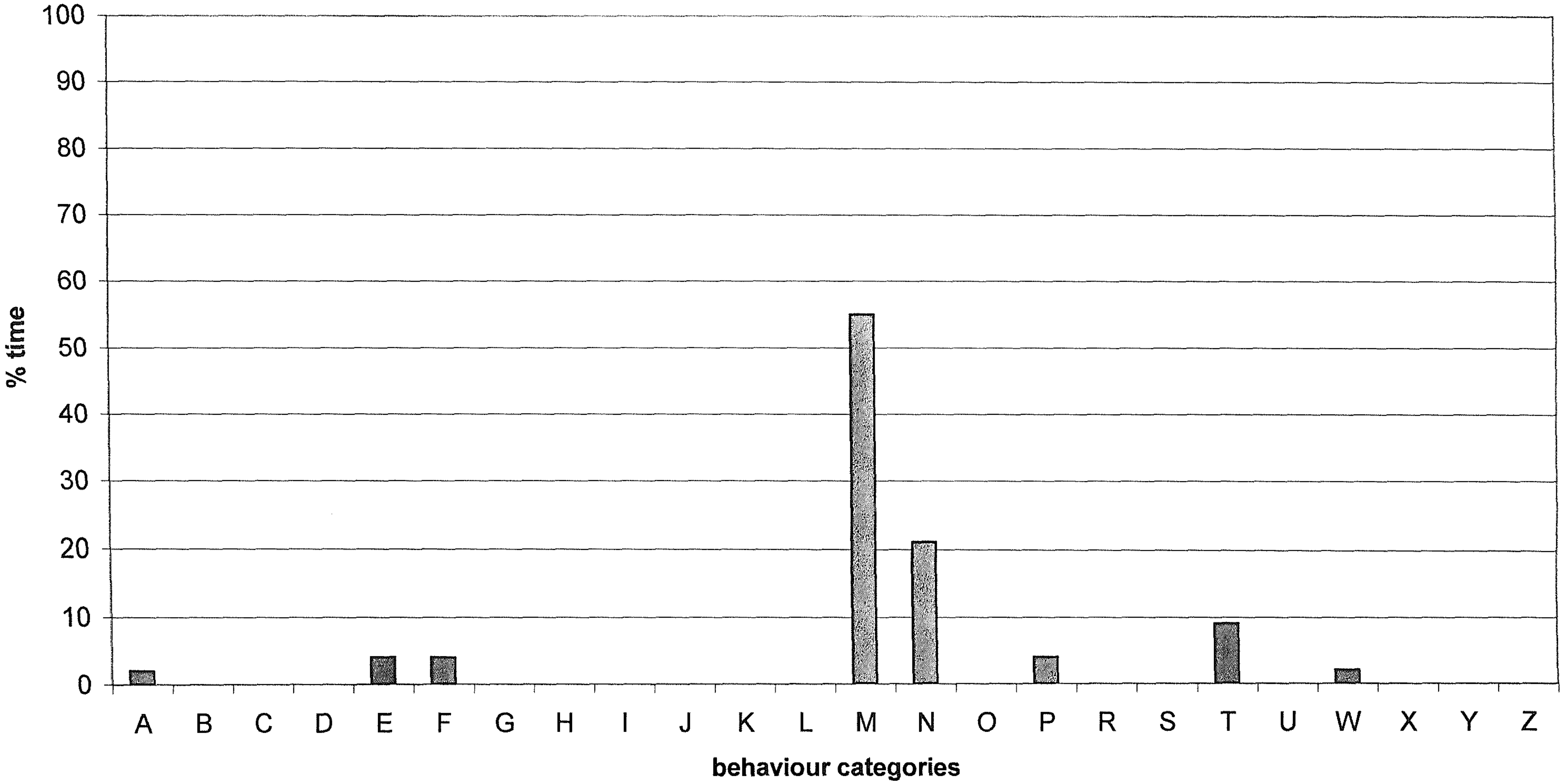
Neil
Behaviour Profile
3 days (Visit 1, Sept 2001)





Neil
WIB Profile
Tuesday (Visit 2, Feb 2002)

Neil
Behaviour Profile
Tuesday (Visit 2, Feb 2002)



Malignant Social Psychology

The only examples of MSP I found during my whole time with Neil and Claire were very minor, two of the four coming from stories Claire reported to me. The first example, which could be labelled 'treachery' was when Claire described worrying that Neil would not agree to go to the GP when a problem was first noticed by herself and his friends. She decided to tell him that the doctor was asking to see all newly retired patients for a check-up.

This was the only example involving Claire. Despite her describing looking after someone like Neil as no more than looking after a cat, and suggesting that she didn't feel he was aware of his situation, just accepting, her style of care did not reflect this.

Two examples were observed at Homemead and the residential home where Neil spent one day a week. At Homemead during a quiz no-one asked Neil for an answer, probably due to his lack of speech. This may be seen as banishment. However, he was included in all other activities, and perhaps also was intended to prevent embarrassment. Another example was a mild but common one, involving the over child-like greeting of patients by a very jolly matron at the residential centre. However, Neil seemed to enjoy meeting her and smiled broadly.

Finally a most telling example occurred during the final week of Neil's life. He was in hospital and a nurse which Claire described as *'blonde, barmaid type'*, told Neil that she would give him a kiss and he could give her a smile. Neil's very limited speech meant that his answer to almost all questions was *'yes'* (which had caused some difficulties in diagnosis of pain etc). So it was to Claire's great delight that Neil looked at the nurse and said *'NO!'* very loudly. This incident, perhaps an example of infantilisation, showed that Neil was aware of the situation and was showing his self respect was still very much present.

Positive Person Work

Claire and Neil's team work showed through in examples of positive person work, with Claire's calm yet encouraging manner helping them to work together effectively.

Examples of facilitation were seen on all occasions that Claire helped Neil with care. Her gentle step-by-step prompting, for example when moving him to the table, *'push down here for me'*, was always followed by Neil and the task completed without difficulty. In working with him she always allowed him, where possible, to do as much as he could himself. For example in shaving she would prompt him to shave himself, tell him what a good job he had done and then perhaps go over one or two areas that he had missed again.

During his time at the day centre Neil took part in various activities, including singing, and showed clear signs of enjoyment – examples of play.

Carer support for intact abilities

As mentioned above, the teamwork initiated by Claire enabled Neil to use the intact abilities he still clearly had. However, these abilities would not have been displayed without gentle prompting from Claire. I also observed this in the day centre where carers prompted Neil to eat unaided.

During my last stay Neil showed signs of what Claire called *'lazy eating'*, a habit she felt he had picked up whilst on respite the previous week. However, with gentle prompting he was able to feed himself again.

Carer validation of emotion

Neil rarely showed emotion. During the whole time I had spent with him I only ever observed occasional signs of positive emotion, for example when joining in with singing he would smile. I never observed any negative emotion. Hence I find it difficult to include any examples here. Claire felt that Neil must be frustrated at times but said that he never showed it, seemingly accepting his condition.

On the first morning of my second visit Claire chatted to me for a while as we exchanged news from the previous six months. After we had spoken she went across to Neil and cuddled him, apologising for ignoring him. This could be seen as an example of validation of an emotion she felt he might be experiencing.

Politeness strategies

The only example of what could be seen as a politeness strategy by Neil was observed during my first visit. I raised my glass of wine and said *'cheers'* whilst making eye contact with Neil. He replied *'cheers'* to me. This was quite a notable event as he had very limited speech and would usually reply *'yes'*.

Aspects of selfhood

On first meeting Neil, Claire told me of his high achievement at work. After obtaining a PhD he had worked for many years on various engineering projects and had received awards for his outstanding academic ability. By telling me of his past, in his presence, she was helping to keep this aspect of his self alive.

A carer at the residential home where Neil spent one day a week told me that before the deterioration in his verbal ability he used to talk about his work. This reminded me of Sabat's participant, Dr B, who had asked for the dates of his meetings with Sabat on *'the project'* to be displayed for all to see (Sabat 2001). Although Neil did not object to taking part in the activities, as Dr B had done, I still wondered if he felt to some extent 'different' from the others because of his past. He was also quite younger than most of the residents.

On my second visit, six months later, there was no mention of this aspect of Neil's life. Whether this was because I hadn't know anything about Neil at my first visit or whether this was a change in how people now viewed Neil, I was not sure. However Claire still handed the newspaper to Neil to read in the morning even though he appeared to only repeat the headlines to himself again and again (which also showed that he could read words and speak them, but that he didn't use words in his talk).

Perception and social death

My observations about Claire's belief about what Neil was still aware of, and the notion of social death are contradictory. In the final interview, after Neil's death, she spoke of how looking after him was *'like looking after no more than a cat'.* She also spoke of being prepared for being on her own after his death *'because you've been on your own for so long'.* In particular she missed *'chat'* due to his lack of speech. She also felt that he had changed enormously and noted that sometimes she felt she was looking after a stranger rather than her husband. This evidence would suggest that to some extent Neil is socially dead in Claire's eyes. However, on recalling an event during the final week of his life she showed that she did not completely agree with this:

'And right at the very end the last week, he was in hospital. And this nurse who was very blonde, barmaid sort of rushed in and said 'come on

Neil I'll give you a kiss and you can give me a smile'. And he looked at her and said 'NO!' this reduced me to hysterics. Something there'.

In her behaviour towards Neil Claire did not act as if she felt he was socially dead, all her actions were of a loving wife and carer, carrying on the teamwork which had, for them, been a life-long affair.

Longitudinal profile

Deterioration in Neil's speech had already occurred by the time of my first visit. His previous discussions with care staff about his work having faded with declining verbal ability. His speech was limited with most replies being 'yes' regardless of the question. However, shortly before his death he showed his ability to make his wishes known strongly by telling a carer 'NO!' Neil's mobility declined over the visits from walking with a stick to requiring a frame and wheelchair. Similarly his ability for self-care declined across time. One exception was his ability to feed himself. On returning from respite just prior to my second visit he was no longer able, but Claire, putting this down to 'laziness', re-encouraged him to eat unaided. Neil rarely showed emotion and this remained constant over the course of my visits, with his well-being and ill-being scores the same at each visit. Neil's relationship with Claire remained one of good teamwork throughout, although she spoke of the change, for her, from 'husband' to 'stranger'.

Résumé

Neil's decline in mobility and ability to care out own care tasks was observed over the visits. His decline in verbal ability had been noticed by day centre staff before my visits, and now was very limited. He spent much of his time in a well-being state of +1, according to the dementia care mapping scale, and rarely showed emotion. On occasion he would have brief episodes of higher level well-being, in particular when humming along to favourite tunes. Observation at both home and day care centres revealed that he carried out a wider range of activities at the day centres. Claire realised this, feeling it was important to send Neil to day care so that he would have the mental stimulation so important to him. Claire was very patient and kind with Neil, and their teamwork during care tasks was testament to that during their marriage. She showed belief in social death to some extent, but this was not translated into behaviour.

From this case study I am reminded of Sabat's (2001) Dr B, whose career in academia was one of high status and Sabat helped to retain that in his time at the day centre, for example by putting a list of the dates of meetings for 'the study' at Dr B's request. Similarly Neil enjoyed talking about his previous work, whilst he was still able, in his time at the day centres. This shows how taking a life history of the person with dementia can be very useful in retaining personhood. Here Sabat and Harré's (1992) concept of self three shows that the person with dementia requires the help of others to retain this part of their lives. When a person with dementia can no longer communicate verbally, for example when Neil could no longer talk about his work, we need to consider alternative ways of retaining this aspect of self. For Neil this was facilitated in part by Claire giving him the newspaper to read daily, but it may have been possible to consider other avenues, for example he was still able to work with this hands, as seen at the day centre.

Mr and Mrs Archer

Background

Mr and Mrs Archer, Monty and Frances, lived in Australia when first married. A twenty stone man, Monty dominated in stature but also in his manner with people. He had been diagnosed with vascular dementia some years ago when in his early eighties.

The vascular dementia mostly affected his short term memory, causing him to sometimes ask repeated questions, for example about how he would get home from the day centre, and whether Frances knew where he was. This caused him some anxiety. An active man who remained engaged with his surroundings, Monty showed little signs of depression, his frustration instead coming out in angry outbursts at carers who were trying to help when he felt he didn't need it, or that Frances should be doing it. A proud man who had been used to servants in his earlier years, his reactions made for difficulties with some carers. For Frances it was just a continuation of the man he had always been.

Both born in Kenya, but not meeting until some 30 years later, they were both brought up in upper class families. Monty's family had owned a very large farm and had a number of people working for them. His manner with people today reflected his past. A forceful, sometimes aggressive man, he often ordered Frances around and had had an influence on her giving up her well-liked career.

They had what Frances described as a *'chance meeting'* at a party in Australia to which her friend had managed to get her an invitation. She had given him her phone number but he had not called immediately as the host had persuaded him that Frances was not for him, she was a career girl. However he did phone two years later and asked her to a dance. She spoke of *'trying not to sound surprised'* when he phoned. Whilst she was recounting the story of the *'slow start'* to their relationship Monty turned to me and said, *'well you've got to be sure haven't you, who you're marrying'.* His first marriage had ended when his wife had an affair with a neighbour. Frances's first marriage too had ended.

Frances had been told about the study by the manageress at Homemead and said she would be interested in taking part. When I spoke to her on the telephone she said her son was concerned about her taking part. I assured her that she shouldn't feel under any obligation to take part but she said she would like to find out more and invited me round for a coffee.

On arriving at her front door I was greeted by a district nurse who expressed concern that I shouldn't stress Frances. I began to feel like an ogre and felt that I would try and persuade Frances there was no need to take part. However on meeting, Frances and I instantly hit it off. A fellow neurotic with an interest in people, we soon chatted as if we had known each other for years. This was the first carer I had felt at ease with this quickly. A journalist by trade, Frances spoke of her excitement at interviewing famous people in her younger days when married to her first husband. Unfortunately the marriage didn't last and Monty, her second husband, did not approve of her career so she wound down her involvement, concentrating on occasional articles and features. She spoke at ease and length about her life and its path crossing with Monty's, saying that I was a good listener and had a skill in being able to go into someone's house as a stranger and extract their life story. She also spoke of her relief that I wasn't her idea of a stereotype psychologist, and that she would be able to reassure her son.

I stayed with the Archers three times, spending time with them in their own home and also at Homemead where Monty spent two days a week. During the visits I was also able to meet some of their relatives, friends and neighbours and to observe Monty's behaviour in their presence. In addition I was able to make some observations outside the visits at other times at Homemead and on their Christmas outings.

Homemead September 2001

Before my first stay with the Archers, during my stay with Neil and Claire Dudley, I was able to observe Monty at the day centre. He had been staying at Homemead on respite for a few days and was, according to the staff, not his normal self. He was asleep in his chair and when he woke briefly he did not appear to have enough strength to move from his chair and went back to sleep. He did manage to answer a few of the quiz questions when he woke. At lunchtime he said he didn't want his lunch, which I later found out from Frances is a sure sign that he is unwell. In the afternoon he went to the toilet and stayed there for over an hour. Staff kept popping in and out to make sure he was OK.

As this was the last day of his respite he was taken home by taxi in the afternoon. I later learned from Frances that on arriving home they couldn't get him out of the car and took him to the doctors. He was subsequently admitted to hospital for a week with an infected ulcer of the leg.

Visit 1, November 2001

I found this visit extremely stressful and tiring. Each night's dictation onto tape reflected my exhaustion. I found that Monty initiated talking to me very frequently and would talk to me for some hours on end, often repeating the same story again and again. Whilst he was having his afternoon nap Frances would talk to me, and I felt like a sponge, absorbing enormous amounts of information for three days.

On arriving I met the district nurse who had warned me not to stress Frances. Her initial frostiness towards me had not thawed and I had parked my car where she usually did, making her walk several extra feet to the front door. She brought with her a junior district nurse who also seemed to be continually upsetting her. This nurse was finding out about life as a district nurse by observing many district nurses at work. Frances, the junior nurse and myself saw the amusing irony of having many observers in one room all observing one another. The district nurse did not.

After the district nurse had dressed Monty's leg ulcers we sat and had coffee until lunchtime, catching up on Frances's news. Monty also chatted to me, telling me that he was born in Kenya where his father had a very large farm and many workers. He repeated this story many times, each time telling me as if anew. When lunch was ready he used his electric lifting chair to raise his position and then moved to the dining room unaided, but slowly.

He ate unaided and continually asked Frances for items of food, forgetting he had already just asked. Frances also talked to me quite a bit over lunch and Monty appeared to become annoyed that he wasn't being served his food fast enough. Frances later told me that he was often like this when other people were present as she felt he wanted to be the centre of attention. I also found his manner very sexist, towards myself, Frances and the district nurses.

However, his sexist manner also translated to very courteous behaviour when we were later entering the local clinic for his blood test. He insisted that I went through the door first and that he would follow on, despite his difficulty in mobility. In the clinic he seemed confused and kept asking if he was seeing a doctor. Each time Frances would remind him that he was to see a phlebotomist and he would be reassured for a few seconds before asking again.

On returning home and whilst Frances made the evening meal Monty spent some time talking to me about his past, his time in Kenya and later at school with his brother. He repeated the story again and again for some hours, later talking about his first wife and her adultery. Frances seemed keen to use the opportunity to have some time to herself by having a bath and then preparing the meal in a leisurely fashion. Although this wouldn't be what would normally happen in the evening – Monty would be sitting in the lounge whilst Frances prepared the meal and would occasionally shout out to her about its progress – it gave me the opportunity to experience time with Monty and to realise how tiring it can be to listen to repeated speech. Although I had only experienced a few hours in the first day I found it enormously exhausting and this gave me some insight into how Frances might find caring for Monty. Later in the evening Monty became concerned that my father may not know where I was. Despite reassuring him he would forget and ask again.

At the end of the day my sleeping bag was a welcome escape. After dictating the days notes I tried to settle for sleep, but Monty and Frances's room was below and I could hear his loud voice booming as he talked to her for some time. I also woke in the night to hear him talking to her. This was the first time I had been woken at night during my observations with couples and I found it very tiring to try and make notes during the small hours.

The second day was spent at Homemead where I was also able to observe Anne Reed and Eileen Jackson. Monty and myself were driven there by taxi where I was able to observe the taxi driver being asked the same question again and again. He had not met Monty before and was very patient in his responses each time.

During the quiz at the day centre Monty's hearing loss was causing him difficulties. He asked Pat, the carer, to read the question out again on numerous occasions and she became very fraught with his repeated requests, finally giving him the book, *'you read it!'* He seemed not to notice Pat's distress.

He took part in the pastry making activity before lunch but became agitated during the afternoon asking repeatedly, *'are we going to get a lecture?'* I later discovered that this was because Frances told him that the day centre is somewhere he goes for his *'social morning'* and that he would probably get a lecture. I later heard him telling the taxi driver *'I didn't think much of this course, we don't learn much here'.*

The final day was spent at the Archer's home, with the same routine as for the first day. The district nurse visited to change the dressings on his leg ulcers. This time it was a different nurse and she told me to look away if I was squeamish whilst she dressed his leg. I had not looked before but this invitation proved too tempting. I had never seen an ulcer before and was horrified (hopefully only inwardly) to observe that what appeared to be half of his lower leg was just open wound. The nurse said that this was the largest ulcer she had ever seen. Fortunately Monty did not seem disturbed by this.

Day trip from Homemead – Christmas shopping – November 2001

At the end of November the staff at Homemead arranged a Christmas shopping trip, followed by a Christmas dinner in a local pub. I often helped out with these trips as a way of thanking then for their help in finding participants for my study. In addition it allowed me to make further observations.

On this trip I was able to observe Monty. Whilst going round Marks and Spencers he noticed the underwear section and pointed out some very lacy pieces saying he would be getting that for Frances this year. Lynda persuaded him to buy a plant instead and he chose a white cyclamen.

At the pub I was able to observe his usual forceful manner. He complained about the speed of the service, which was very slow, saying loudly, *'good service in here!'* When his Christmas pudding arrived he complained that it was too hot. The staff appeared to be irritated by his manner.

Day trip from Homemead – Christmas shopping and Harry Ramsden – December 2001

Every year the staff from Homemead arranged a Christmas shopping trip followed by a meal and entertainment. On this particular outing Monty and Neil Dudley were present.

As I was looking after Neil I didn't manage to observe Monty at great length and at the meal we were separated into two tables, with Monty on a table for two with the coach driver. He sung along to the carols, but at times during the meal he looked bored and restless. At one point he tried to get up, perhaps uncomfortable in the small chair.

Visit 2, July 2002

This was a two day visit as I was now working part time and had to fit visits around my teaching schedule.

I arrived on a beautiful Monday morning to find Frances, her son and Monty's daughter by his first wife in the lounge with Monty. With the exception of Monty we went outside for coffee. Monty told me that he wanted to go outside but Frances found it too cumbersome moving him outside and so waited until nearer lunchtime. I wondered if she wanted some time alone with the relatives. However, this shows that he was no longer always able to move around without the help of others.

Whilst we were outside she updated me on the events of the past eight months. She described him as *'a bit more trouble'* and spoke of an incontinence accident he had at Homemead when he couldn't get to the toilet in time. However, she said that the large ulcer on his leg had improved. She also felt that he was currently quite alert as there had been lots of activity in the house at the weekend with his daughter visiting from Switzerland. Other relatives and friends had been visiting on and off all weekend, and this was to continue during her visit to the country.

Monty did appear quite alert at lunchtime when he came out to join the gathering. He recognised his niece who turned up and seemed pleased to see her. He was also still able to feed himself. However, with such a number of people present he appeared unable to always hear what was being said and although he would occasionally ask he did appear to be slightly isolated in this respect.

He went in for his afternoon nap when the relatives left and then joined me again outside whilst Frances prepared the evening meal. He was content to sit and do a crossword puzzle and read the newspaper, occasionally talking to me about the headlines and also telling me about his childhood again.

Frances told me when we were alone that he had become very cross with one of the carers who helped to get him showered in the morning, telling Frances that he didn't need help. She said she replied that she did and this was why a carer came in, but it appeared that he was not happy with anyone except Frances helping him. She also explained that she didn't always sleep downstairs, only when he was ill, as he couldn't get up the stairs anymore now.

When the evening drew to a close Monty announced he would be turning in, but seemed disorientated and said that he didn't know where his bed was. However he didn't appear distressed by this, walking towards it saying *'I think it's over this side of the house'*.

The second day was spent in Homemead, Frances telling Monty that it was his *'social morning – perhaps you'll get a lecture or something'*. But before we left in a taxi I was able to observe Monty becoming cross with the carer. As she went into the bathroom to help him wash he shouted, *'get out of here! I don't need anyone to help me!'* before leaving the bathroom the carer shouted back, *'you'll talk to me with respect!'* Then Frances went into the bathroom as if nothing has happened announcing *'morning Monty!'* followed by the carer also acting as if he must have forgotten, *'morning Monty!'* The carer explained to me later that this was how they dealt with his aggressive outbursts.

The district nurse then came to dress his ulcers and I too noticed it had got much smaller, with the island of flesh amongst the wound which had been very small before now much larger. During the dressing Monty made jokes about women now wearing trousers which he found amusing but the district nurse didn't and she looked despairingly at me.

One difference I noticed on this visit between his behaviour at home and at the day centre was that he doesn't sleep at the day centre, which may mean that he is more stimulated in this environment.

Visit 3 – November 2002

This visit was my final 'residential' visit of the whole study. A two day visit, I had mixed feelings about this being the final one. On the one hand it signified the end of a very special study time, but on the other I found the visits extremely exhausting, and now that I was working part time I would usually have to go straight from a visit back to teaching. When I was at the university I could have some much needed time to unwind alone before facing the world again.

On arriving at the Archers I met the district nurse who was taking a blood sample from Monty. Frances popped out to the shops and left me to chat with Monty. He was reading a book by Rider Haggard – I had seen the book on one of my previous visits, his son had bought it for him and had got Rider Haggard to sign it and put a message to Monty inside the front cover. He became quite anxious that the book actually belonged to Rider Haggard and that he should write and thank him for it. He repeated this several times. I later learned from Frances that he had become angry one evening and ripped a page out from the book, but didn't know why he had done it.

When Frances returned she updated me on progress. She felt that there had been a positive change in that he was now suggesting that he should get up and walk round a little, that it might do him some good. She felt this showed some insight.

Whilst Frances prepared the lunch Monty moaned that it was going to be late. I noticed that he was able to walk to the dining room with the use of his frame, but unaided. An improvement from last time. During lunch he became annoyed that Frances was talking to me too much. Frances later told me that he often did this when she had friends round. She said that he would not join in with conversation but he didn't want her to have it either.

After his afternoon nap he sat and chatted to me whilst Frances prepared some afternoon tea. He spoke at length about his brother – a story I had not heard before. He spoke of how jealous he was that his brother had his father's name as his middle name, and Monty didn't. The youngest of four, Monty was from what he called a *'balanced'* family of two boys and two girls. He said in a very matter of fact tone that he didn't know whether they were dead or not but that he expected that they were.

At this visit I also noticed how often he said he was useless. This was something I hadn't heard previously. The first occasion he mentioned it to me was when he was trying to do a crossword puzzle.

Later that evening when Frances was talking to me about when she first began her career as a journalist Monty kept interrupting. This was clearly something he didn't like her talking about. However she obviously was very proud of her work and told him, *'oh let me just finish this story, I've got a good listener'*. She then took me out to the hallway where she had kept her first ever article. Monty came out into the hallway wanting to get past. He was clearly annoyed at Frances showing me the article.

The second and final day of the visit was spent at Homemead, after the district nurse had dressed Monty's leg ulcers. He made several sexist comments about women wearing trousers which the nurse chose to ignore and made faces at me, giving me knowing looks.

Monty seemed to enjoy the day at Homemead, speaking to one of the residents over lunch. In the afternoon we played bingo and he was able to follow the number calling and marking his own card, although he often had to ask for the number to be repeated because he hadn't heard it properly the first time. The caller was a new staff member who was patient and very good with the clients.

Monty asked me a couple of times during the day if Frances knew where he was and how he would get home. Each time I explained he seemed relieved and grateful, thanking me.

Frances's interview – March 2003

When I went to visit Frances to interview her it was one of the first beautiful days of spring. Monty was having his afternoon sleep and she suggested we sat outside. Unfortunately the gardener was mowing the lawns at the back of their house so tape recording the interview was going to be impossible. However I made the decision to continue with the interview in a place where Frances felt comfortable and make notes. She was at ease during the interview, quite possibly as this had been her way of finding out about people during her career. After leaving the Archers I made further notes by dictation onto tape on the way home.

How it began

AC *Can you remind me – when did you first notice Monty's illness?*

Frances had first noticed that something was wrong when they were living in Australia. She spoke of how he began to *'drive oddly'*, seemingly not knowing what to do. For example she said he would drive up to a roundabout and become *'stuck'*. In one particular incident he had arranged to pick her up in the car and couldn't remember where to pick her up and became quite confused. Subsequently he broke his hip and became very confused after the operation. He was diagnosed with vascular dementia.

Frances's knowledge of dementia at that time

AC *What did you know about dementia then? Had you any experience of other people with dementia?*

Frances explained that her mother had been ill and that retrospectively she felt it was some form of dementia. She said she wished she'd been more patient with her, although as she told me how she used to care for her, listening out for her via a baby alarm it sounded as if she had been very patient.

Changes in the person and their spousal relationship since the illness

AC *Do you feel Monty has changed in any way during his illness?*

She said that he still tries to *'wind me up to get a reaction'*. He used to before, but not quite as much as he does now. She said she thought that Alzheimer's Disease, rather than vascular dementia, changed people's personalities. However, she spoke of how he was currently much more emotional than before, for example bursting into tears on coming home from respite.

How does the carer see their relative's quality of life?

AC *How would you describe Monty's quality of life since his illness?*

Frances spoke of how he had become aware that she had taken over everything in the running of the house, leaving him with little to do. She had tried to find some jobs for him, such as cleaning the brass, as he had wanted to do something. This implies that she feels his life lacks a sense of purpose in this sense, because of his disabilities.

Communication since the onset of dementia

AC *What has communication been like between you and Monty?*

We spoke (as we had before when alone) about the differences between men and women in communication. She described how she noticed on their honeymoon that there was no conversation. She feels that now she can't *'chat'* and said, *' you can tell him something but he will interrupt with a question – 'how old am I'?'* So she said she didn't bother. She spoke of how he was always after attention and had discussed this with her son, wondering if he sought attention because she no longer chatted, *'it's his way of keeping in touch'.*

Recognition

AC *Does Monty recognise you and your family?*

Frances said that he recognised some of the family, but not all. And that he *'craftily pretends to'.* I had seen him recognised his niece, calling her by name.

Does the carer think the person with dementia still knows what's going on? Do they have insight?

AC *Does Monty ever have any lucid moments? Can you give an example?*

Frances spoke of a recent moment of clarity, of remembrance of knowledge from a long way back. A neighbour was visiting, had eaten a banana and wanted to place it on a tree as she said it contained potassium. Monty spoke up announcing, *'you also need nitrogen and phosphorus'.*

She added that she didn't feel he knew about his illness and was happy. He had once said to me that he was a very happy man, but I felt he was trying to convince himself he felt OK.

She said that he would sometimes ask for his mother, although he had not spent much time with her in the past. She had been killed by a stranger, but he did not seem to talk about that, perhaps not remembering.

What has it been like for Frances?

AC *What has it been like for you looking after Monty?*

For Frances the hardest part was his lack of chat and possessiveness. She said he made her feel guilty even if she was just going to pop out to see a neighbour, but her son had said that she needed to have her own life too. However, when she arranged for a carer to look after him whilst she had a day out he would sometimes become very rude and angry with the carer so she felt this was difficult.

Summary of findings from visits

Well-being and ill-being profiles:

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

	Visit 1	Visit 2	Visit 3
Making wishes known	2	2	2
Initiating social contact	2	2	2
Warmth and affection	1	1	1
Self-respect	1	1	1
Being helpful	0	0	0
Humour	0	1	1
Bodily relaxation	1	1	1
Creative self-expression	0	0	0
Showing pleasure or enjoyment	1	1	1
Responding appropriately to others	0	0	0
Expressing appropriate emotions	1	1	1
Holding their own socially	2	2	2
Alertness, responsiveness	2	2	2
Being active	2	2	2
Being purposeful	2	2	2
Total	17	18	18

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

	Visit 1	Visit 2	Visit 3
Depression or despair	0	0	0
Intense anger	0	1	1
Grief	0	0	1
Anxiety	1	1	1
Fear	0	0	0
Boredom	1	1	0
Physical discomfort / pain	1	1	1
Bodily tension	0	0	0
Agitation	1	1	1
Apathy and withdrawal	0	1	0
Distress	0	0	0
Cultural isolation	1	1	1
Difficulty withstanding powerful others	0	0	0
Total	5	7	6

Monty's scores for both well and ill-being remain consistent across the visits, reflecting little change in his situation.

His moderate scores for well-being are mainly reflected in his continued active engagement in the surroundings. A forceful man by nature, Monty is not afraid to seek and initiate social interaction in all situations. A man who talks and dominates rather than listens, he is often viewed negatively by carers and nurses. This is reflected in the episodes of malignant social psychology detailed later. However, I would argue that this does not have such an effect on his well-being as it might with a person of lesser self esteem since he does not seem to react to these episodes. He seems to be fairly insensitive to the emotions and reactions of others, but this may serve as a protective function for himself. His ill-being scores, consistently low, would corroborate this.

His ill-being scores show a man who is, at times, anxious in certain situations. This anxiety was mainly shown in the day centre when he was concerned that Frances may not know where he was or that he would not be able to get home. This anxiety was also accompanied by signs of agitation. Occasionally bored at the day centre he would still actively seek experiences.

At home his ill-being scores reflected the anger he showed on occasion towards some of the carers. Perhaps a consequence of his upbringing he appeared to show little respect for some of the carers and their feelings. Only once did I observe signs of grief for his lost abilities, calling himself *'useless'* at my last visit.

Finally I observed Monty to be isolated in terms of his difference in upbringing and also his hearing difficulties. Both on occasion caused some isolation although he only seemed concerned when this isolation was from his relatives when his lack of hearing caused him to miss out on conversation.

The Behaviour rating scale for Psychological and Social problems (BPS)

	Cognition/44		Mood/28		Social contact/20		Total/140	
	FA	AC	FA	AC	FA	AC	FA	AC
Visit 1	34	17	8	10	13	3	73	38
Visit 2	30	19	11	10	13	7	71	49
Visit 3	32	25	15	13	10	10	78	61

FA = score as assessed by Mrs Archer
AC = score as assessed by the author

The differences reflected in the cognition scores are quite marked. On reflection I feel that my scores are rather lower than I would have retrospectively given. Nevertheless the scores reflect what I saw at the time of my stay rather than my overall view of Monty. Here some of the differences may occur because, for example, I did not engage Monty in conversation but left it up to him. Hence his conversation to me appeared coherent. Frances on the other hand may be scoring from the perspective of someone who has actively tried to get Monty to answer certain questions, not just to allow him to talk about his past.

The mood scores are much more in agreement, and in line with the well and ill-being scores, since a lower mood score on the BPS reflects a higher level of well-being.

The earlier differences in social contact scores I believe are reflected in my scoring Monty from his behaviour in his own home and the day centre. Frances had not seen Monty at the day centre, but felt that he was more stimulated there. My later higher scores reflect the difficulties I felt he was having in social contact in activities due to his hearing difficulties.

The Bristol Activities of Daily Living (BADLS)

	Total score/60	
	FA	AC
Visit 1	29	23
Visit 2	26	26
Visit 3	26	26

FA = score as assessed by Frances Archer

AC = score as assessed by the author

The scores from the BADLS are fairly consistent over time and between Frances and I. This is in line with my observation that his mobility remained fairly constant, with a slight decrease at visit two followed by an improvement at the final visit. His ability to feed himself remained constant. In terms of personal care he was still able to use the toilet on his own, and could wash with assistance, but often resisted help in this area.

Dementia Care Mapping

Unfortunately I quickly discovered that mapping at the Archer's was going to be almost impossible. Both Monty and Frances spoke to me for a large proportion of my visits, which meant that I had to keep my attention on the conversation rather than try to divide it between mapping and conversation. This highlighted one of the difficulties with this kind of observation, that the researcher provides another source of conversation, or as Frances put it, *'I dump stuff on you'.* Frances also spent quite a bit of time out of the room where Monty sat, and he would always initiate chat with me. Whilst this is obviously not an observation of what would usually happen it is nevertheless a reflection of some of the underlying tensions and dynamics between the couple.

In afternoons where Monty was in his own home I could have mapped an hour or so as 'N' (sleep), but I was not in the same room so could not see if he was actually asleep or distressed etc. Hence I had to make the decision that in a household with high negative expressed emotion it would not be possible to be a participant observer and to map at the same time.

Malignant Social Psychology

There were several examples of malignant social psychology across my visits. One of the ones which I felt caused continuing problems for Monty could be described as 'treachery' by Frances. For her best reasons Frances tells Monty that his visit to the day centre is a *'social morning'* and that he may get a lecture. On many occasions I observed Monty at Homemead asking if there would be a lecture, and also commenting that they didn't learn much on this course.

Banishment was observed in Monty's own home as a gate had been set up (on doctor's orders) so he could not try to go upstairs due to his mobility problems. This also lead to an example of withholding as Frances, who had originally joined him in sleeping downstairs later began sleeping upstairs unless Monty was ill. At a later visit his mobility caused banishment from the garden when his relatives were present, as Frances felt it was too difficult for her to keep moving him. On this occasion when Monty did get out into the garden to sit with his relatives his hearing difficulties lead to an example of 'ignoring / outpacing'. Whilst some of his relatives would try and repeat the bits of conversation he had missed others would be caught up in the pace of the conversation and carry on regardless.

His hearing problems played a part in one of the most severe examples of malignant social psychology when a carer at the day centre became exasperated with Monty. He had asked her to repeat some of the questions from a quiz because he hadn't heard them the first time. In front of all of the other clients she thrust the book into his hand saying *'you read it!'* However, this did not appear to upset Monty.

A further 'severe' example with a different carer occurred when she tried to go into the bathroom to help Monty wash one morning. He became angry, feeling that he did not need help and shouted at her *'get out of here!'* She replied *'you'll talk to me with respect!'* before leaving.

Positive Person Work

I observed very few examples of positive person work during my visits. This could be, in part, due to Monty's forceful nature which was often interpreted by carers as very rude. Frances was used to this manner and did show some aspects of good care, for example in helping him to keep up with the plot during watching television, enabled him to watch for longer.

One of the new members of staff at the day centre was very patient and understanding with Monty's hearing problems. She very carefully read out and repeated numbers during a bingo game so that he could hear them and remain included in the game.

Carer support for intact abilities

As the above examples show, there were occasions where carers helped with activities so that Monty could take part using his intact abilities.

Frances would often ask if he wanted help but then allow him to carry on himself if he said he didn't. She also felt that he had noticed that she had gradually taken over the running of the house and tried to find small jobs that he was still able to do so that he felt useful. As she knew he could still read (although he would forget what he had just read and repeat the same page) she would find him books and always give him the newspaper.

Carer validation of emotion

Frances's patience with Monty when he asks repeated questions when feeling anxious shows that she is validating his emotion by trying to reassure him each time she answers.

When he was first home from hospital the doctor agreed to let him return if he was prevented from going upstairs. As a result his bedroom was moved to the dinning room. At first Frances joined him in sleeping downstairs, which could be seen as an example of solidarity, of validating what he must have felt, but she later returned to sleeping upstairs unless he was ill.

On the whole Monty's anger was never validated. Frances's strategy was to ignore it and carry on as if he hadn't been angry – a strategy she may have used over the years of her marriage. Other carers became angry as well, failing to validate his emotion.

Politeness strategies

Despite his sometimes aggressive and domineering manner Monty would also show signs of politeness. The other side of his sexism, reflected in jokes, would be shown when he held the door open for women, despite his own mobility problems.

When I reassured him during his more anxious moments at Homemead he was very appreciative and thanked me each time, *'thank you* very *much'.*

Aspects of selfhood

Monty appeared fiercely proud of his past, of his father's farm. He often spoke about them. His manner, a legacy of this past, in a society dominated by men and the upper classes, caused problems with some. Frances, also from this background, was much more used to the manner and often chose to ignore it, although she had sacrificed her career following his insistence.

Some aspects of his past caused him difficulties in his current situation, for example his first wife's infidelity seemed to be still at the front of his mind, and he mentioned it on occasion. This may have contributed to his insecurity and possessiveness towards Frances, something she found difficult at times.

Monty's angry outbursts could also be seen in the light of his past experiences. Used to giving orders to servants he seemed to find it difficult to accept help when he hadn't asked for it. The respect he had once commanded was now being asked for by carers. His discussion with me about how he was *'useless'* may reflect his current feelings as his dominance is slipping away. His situation can be contrasted with that of Gilbert Woody, who despite his failing abilities is still very much treated with respect, as head of the family. Perhaps a status he earned rather than demanded.

Perception and social death

At my last visit Frances spoke of wondering what it must be like to be Monty. This discussion was prompted because she had just recounted an incident in which he had become angry with a relative. She also validated some of his emotions, realising that he must be frustrated not to be able to keep up with plots of television, for example, and also that he must become anxious at times when he is confused. For her, patience seems to be important when dealing with someone with dementia. This was highlighted in her interview when she spoke of wishing that she had been more patient with her own mother, who had dementia.

However her treatment of Monty could be seen as invalidating on occasion, for example in ignoring his angry outbursts. But I do not see this as an indication that she in any way sees Monty as no longer a person, since this appears to be the way she has behaved towards him throughout their marriage. As she said in her interview, he hasn't changed in his manner.

One exception to this was that she felt she was no longer able to have a conversation with him, to chat. *'You can tell him something but he will interrupt with a question – how old am I?* So she said she no longer bothered. However, again this appeared to be a continuation of his existing traits as she spoke of noticing on their honeymoon that he didn't chat. She did wonder whether his attention seeking with her was *'his way of keeping in touch'.*

In contrast to this she spoke of feeling that he didn't know about his illness and that he was happy. This would be in line with her 'disguising' the day centre as a *'social morning'.*

Longitudinal profile

Monty's ability was hampered by, amongst other things, his large leg ulcer. By my second visit he was no longer able to walk unaided and had to remain seated until helped. However, at my final visit he had improved and was once again able to walk with a frame. This change was reflected in his slight decrease in ill-being during the second visit. His well-being score remained constant throughout, reflecting his continued active engagement, as did his ability to communicate verbally. His forceful nature appeared to render him immune to the effect of interactions of others. However, his vulnerability showed in insecurity towards his relationship with Frances. This was a legacy of his past however, rather than a change due to dementia. Their relationship remained tense throughout, following its previous pattern.

Résumé

Monty's mobility difficulties were shown to fluctuate across the visits, with an improvement seen between visits two and three. He showed the same level of cognitive ability in terms of speech and self care tasks across the visits. He showed good levels of well-being for most of the time, but some sadness and agitation on occasion. His domineering manner, not changed by dementia, alienated him from others at times. Frances showed belief in social death to some extent and similarly this translated in behaviour on occasion.

A key aspect I felt Monty's case demonstrated was how the person with dementia's previous life experiences can affect their well-being in dementia. For Monty the ending of his first marriage, following his wife's adultery, left him insecure in relationships as shown by his questioning of Frances. As Kitwood (1997) points out, when a person is vulnerable their psychological needs important in the maintenance of personhood may surface. So again, the importance of understanding a person with dementia's previous life experiences may shed light on some of their current day behaviours.

Mr and Mrs Reed

Background

Thomas and Anne met in Holland in the 1950s. Thomas was a member of an army band who were playing in the town where Anne lived. Sat at the same table they instantly hit it off and were later married.

Anne was a beautiful and gregarious woman who enjoyed parties and the company of others. However illness changed her life. When I first met her she was nearly 70 and had bad arthritis and Alzheimer's. No longer the willing host she now wanted to spend her days in bed, sleep being an escape from her pain.

On meeting Thomas at the Homemead coffee morning I was struck by his willingness to take part. I had thought that only people who were coping well with caring would be keen to take part, but Thomas changed my view. He was adamant that I should visit and see how difficult it was for someone caring for their relative with dementia. He booked my visit straight away.

My first and only stay at the Reed's was, for me, a difficult one. I had come across examples of malignant social psychology during visits to various day centres over the years but I had never come across such examples in someone's own home. I felt an extreme unease at witnessing the relationship between Thomas and Anne and observation seemed at times voyeuristic. But I was not just an observer, I became a participant in both positive and negative ways: I comforted Anne throughout my stay, often holding her hand and providing the much needed reassurance that she seemed to lack; however I also went out on the evening Thomas insisted that I should go to his next door neighbour whilst he visited friends. Anne, although only next door, was left alone in bed. This for me was a very difficult situation. On the one hand I was observing and should not pass judgement overtly. On the other hand I disagreed with what I saw.

However, although most of Thomas's behaviour towards Anne would strongly suggest that he felt she was 'no longer there', socially dead, some of his actions suggested otherwise. For example he would always apply her make-up before she went out and choose smart clothing as he knew how important her appearance was to her. He would also polish her nails and dye her hair to this end. During my stay he expressed his feeling that Anne did not know what was going on and that what people said around her went over her head. The case study details observations which suggest otherwise. Speaking with him after her death he appeared more undecided about some aspects of social death, including lucid moments.

Anne suffered a heart attack during an operation on her hip and hence was taking into residential care at Homemead before my second visit. I was still able to see Anne on a number of occasions at Homemead when I was visiting some of the other couples. My visits chart the course of her sad life until death.

The one happy memory I have of Anne was the last time I saw her, after her operation, in Homemead. Her pain had gone and she was able to live the final days of her life in relative calm.

Visit 1, July 2001

This three day visit was to be one of the most difficult, yet enlightening visits of the whole study. I arrived on a Sunday morning, met Anne, and had a brief lunch before we got ready to drive to their son's house, some 30 miles away in the country. I was immediately struck by Anne's ill-being, noticing that she seemed to spend most of her time in a WIB state of –1 or –3. She was not keen to make the journey to her son's saying, *'no, I'll stay here, just let me lie down'.*

Her speech was quite comprehensible, but she often used the word *'whiskey'* in place of other words. I later found out from Thomas that in the early stages of her illness she had been drinking a bottle of whiskey a day. Her neighbour repeated this to me one evening.

A very affectionate lady, Anne would sit and hold my hand telling me that I was *'very pretty'*. According to Thomas she had always taken pride in her own appearance and he had taken over this task, applying her make up daily, painting her nails and dying her hair frequently.

This kindness in helping her to retain her beautiful appearance was not transferred into day to day interactions. I found Thomas a continual source of malignant social psychology examples, the most unnerving for me was telling me that he had a lover (a friend of Anne's) whilst in Anne's presence.

Anne clearly found the journey to her son's unpleasant, not helped by Thomas's unkind taunting, but recognised the village as we approached it. She was, however, pleased to see her son and cuddled him with affection. At her son's she also showed signs of discomfort, asking to lie down but not being allowed. She reverted to her native tongue, Dutch, on occasion – something which her son had not noticed before.

Back at home she ate dinner, cutting it up herself and then using a spoon to feed herself. As soon as she had finished she asked to go to bed, finally turning in at 8 o'clock.

Thomas and I were later joined by one of his neighbours, Dora, and we sat drinking wine and making conversation. I enjoyed the evening and was amazed at the drinking stamina of Thomas and Dora. They were similarly amazed at my attempts to not drink too much, *'but you're a student!'* Another difficulty of participant observation is highlighted here. The wish to 'fit in' with the family and their habits which may be different from the researcher's own. However, I had to remember that I still had at least 45 minutes worth of writing up the day's events once I'd gone to bed.

The second day was spent on an outing arranged by the local Alzheimer's society to a manor house. Anne was keen to know if the journey was going to be as long as the one to her son's, *'it wont be like yesterday will it?'* She had wanted to sit on an isle seat on the coach, but Thomas wouldn't let her, making her sit in between him and myself.

On the coach she was clearly anxious about travelling, sitting forward in her seat and refusing to relax when Thomas told her to. At one point she became very cross with him and dug her nails into his hand. He told me that she usually did this out of other people's sight but that lately she didn't seem to care if people saw her doing this.

At the manor house, wheeled round the grounds in a wheelchair by Thomas she was also very anxious, wanting to know if the coach had left. She relaxed briefly when having a cup of tea and cake with one of the organisers from the Alzheimer's society, Agnes, who Anne seemed to recognise, announcing *'this is nice'*. Thomas was telling Agnes that he had a *'built in babysitter (myself) tonight'*, as he was going out. Anne looked embarrassed and I found myself sticking up for her saying, *'yes we're having a girls night in'.*

The coach journey back to the Reed's home was a little easier for Anne as she insisted on sitting on an aisle seat telling me, *'I wanted to sit there before but Thomas told me off. I wanted to be able to see more'*. I asked if she could see more now and she replied, *'oh yes!'* Thomas's sarcasm was still present as he produced yet more examples of malignant social psychology announcing to Anne loudly, *'you are such a joy to take out'.*

Once home again Anne went to bed after dinner and Thomas told me he was going out to meet some friends. I was happy to stay in with Anne but he told me he'd phoned Dora, the next door neighbour, and she was expecting me to come round. I felt uncomfortable as we both left the house, locking Anne in. Thomas told me he did this when he went out, and that Dora kept an eye out for Anne. He had also given me two bottles of wine to take to Nora's.

At Dora's I was able to relax as she talked to me about Anne in her younger days. Dora and Anne had been great friends. She also spoke of Anne's drink problem in the early part of her illness. I got the feeling that Nora didn't approve of Thomas's new 'partner'. On returning next door as soon I felt able to leave Dora, saying I was tired, I looked in on Anne, and she was asleep.

The final day was spent firstly at the doctors where Thomas insisted that I came into the consultation. The GP didn't seem to mind, being interested in my participant observation study. Here I was able to witness further malignant social psychology from Thomas as he spoke about Anne as if she wasn't there. The doctor was, however, very kind to her and often touched her hand to reassure her. Thomas was keen to find out if anything could be given for her anxiety and so the doctor suggested increasing the dose of Risperidone she was already taking. He also decided to stop the anti depressants she had been prescribed.

Afterwards we went to Homemead. Anne came in with me and kept telling the staff that I was her friend. She insisted that I sat down next to her and when I got up to help the staff as usual she would not let anyone else sit there, announcing that it was *'my friend's seat'*. Anne was very anxious during the morning, asking when we would be going home, although becoming engaged for a short while in a weaving activity, showing her coordination was still very good.

After lunch she told me that when the bus driver came, *'You must stand up straight away. You must do what I tell you and then we can go'*. She must have had some insight to her own cognitive difficulties as she told me that I would have to tell him how to get home because, *'you can communicate better'*. She kept her eyes on the door and if anyone came in she would rush up to them asking if they were the bus driver. When the driver, Alan, eventually turned up she recognised him immediately and flung her arms around him saying, *'oh you have made it all good!'*

On the way home she noticed that Alan had taken a different route. She became anxious but he reassured her, telling her that he needed to drop a parcel off. At her house Thomas came out to greet us, asking if she had had a good day. In front of the others on the bus she said, *'oh yes'*, but the minute we had stepped through the front door she said, *'it was horrible – I'm never going again'.* She then went up to bed.

Visit to Mr and Mrs Dudley – September 2001

On my first visit to the Dudley's I went to Homemead for the day and was also able to observe Anne at times.

I first spotted her as I came in with Neil Dudley. She was looking very very smart as usual and was seated in one of the easy chairs. She didn't seem to recognise me, and didn't smile when I said hello.

During the exercise session which always took place at the start of the morning once everyone had arrived Anne did not take part. When a member of staff asked her she waved them away and said she was in pain. Afterwards she asked to go to bed but was not allowed. However, as with the weaving when I first visited her she sat and painted later that morning and became engaged in the activity for a short while.

Visit to Mr and Mrs Jackson – October 2001

During my second visit to the Jackson's I was able to observe Anne briefly whilst as Homemead. She appeared to be having very bad day and be in a lot of pain. I sat with her and she pointed to her stomach and leg saying, *'I have pain I want my whiskey'* (I think whiskey on this occasion meant bed). I spoke to one of the carers about her and was surprised to hear that they used to think that Anne was annoying but had recently realised that she was in a lot of pain and felt sorry for her.

Visit to Mr and Mrs Archer- November 2001

On my first visit to the Archer's I spent the day at Homemead and was also able to observe Anne during the day. She had been staying at Homemead for three or four weeks, Thomas being on holiday with his partner, Tanya. Anne knew where her bed was and kept trying to go upstairs to lie down. I went up to see her on one occasion and she was just lying on her bed. A member of staff persuaded her to come downstairs for a cup of coffee a little later. She spent the rest of the day quietly, often sleeping in the chair.

Day trip from Homemead – Xmas Shopping – November 2001

The staff at Homemead had arranged a Christmas shopping trip, followed by a Christmas dinner in a local pub. I often helped out with these trips as a way of thanking them for their help in finding participants for my study. In addition it allowed me to make further observations.

I met the bus at the shopping centre and helped to assist the clients off of the bus. Anne was in a wheelchair and said she wanted to stay on the bus. This was her final day on respite as Thomas was returning from holiday. I noticed that she was not as smart as usual and her make-up had not been applied as Thomas would.

A staff member told me that Anne used to be aggressive towards the staff, pinching them when angry. However, the staff, Thomas and other friends had noticed that Anne no longer seemed to have any *'fight left in her'*, and she was no longer aggressive.

Visit to Mr and Mrs Dudley – February 2002

My second, and final, visit to the Dudley's took me to Homemead for a day where I was able to observe Anne. She had had a hip replacement operation and was looking very well. The operation had been difficult and she had suffered a heart attack during it. She told me *'I am better'.* She was now resident at Homemead following the operation.

She helped with some handicrafts in the morning, cutting out shapes. On occasions she smiled. At lunch I noticed that she was being helped to feed herself and she seemed to be enjoying the food saying, *'it is good'.*

In the afternoon I was able to sit with her for a while and noticed her nails were painted. I mentioned this to her and she replied after a little while, *'I still want to look pretty in here'.* We sat together quietly for a while and she said, *'I am so pleased you are here with me'.* She also spoke of *'someone visits'.* I am assuming she was referring to Thomas.

It was lovely to see Anne looking so well. For the first time since meeting her I would say that I did not see her in a negative state of ill-being during the whole day. That was the last time I saw Anne as she died a few months later from a massive heart attack.

Thomas's interview – March 2002

I wrote to Thomas asking if he would be willing to be interviewed and he telephoned the next day saying he was about to go abroad for a few months and would I be able to come down straight away.

His strong voice was easy to hear on the tape and I was able to make a full transcription.

How it began

AC *'Can you remind me when you first noticed about Anne's illness'.*

TR *'The first time it became really apparent was in 96. It was her birthday and I laid on a – it was a very big house, my daughter's house, and I, a lot of people she knew very well, you know, she didn't know them'.*

He went on to describe how she didn't recognise her friends and he found that strange as, *'they were really really good friends'.*

Thomas's knowledge of dementia at that time

AC *'What did you know about dementia then? Had you come across it before?'*

TR *'Oh no. It was my daughter and my son who said you know, Mum's got something wrong with her. She keeps on saying the same sort of phrases'..*

So Thomas made an appointment with a specialist.

AC *'So you hadn't had any experience of people with dementia?'*

TR *'No not really, my grandmother had dementia but I I was away in the army, I never really saw it you know.'*

Changes in the person and their spousal relationship since the illness

AC *'During the time that Anne was ill did you feel that she changed at all?'*

TR *'Oh yes yeah definitely'.*

I asked in what sort of ways she had changed. And he replied that she could be very aggressive at times, seemingly without reason. He gave an example:

TR *'You know I'd say well perhaps we'd be in a house, and she'd want to go, and she'd say to me, you know, let's go, and I'd say yeah in a minute and she'd get hold of my hand and just dig her nails in'.*

He also felt that her continual repeating of things and saying what he called *'stock phrases that she'd sort of learned by heart'* like *'you are pretty'* to get round her communication difficulty.

She was no longer able to spell things and she had had perfect spelling previously.

Thomas also noticed that up by her bed she had a little diary which she'd started to write words down to try and remember.

We then spoke of how Anne took pride in her appearance and how Thomas had to get her ready in the morning.

TR *'You see the thing was she was always she would never walk outside the door unless she was properly dressed. You know and she wouldn't go anywhere she would never go to the shops without having her hair done and those sort of things. That was just her nature'.*

So this was an aspect of Anne which stayed the same with Thomas's help.

Later in the interview Thomas spoke of Anne's love of reading and doing crossword puzzles.

TR *'One thing that was very fascinating was she was a absolute avid reader you would never find her without a book and she loved* <u>loved</u> *doing crosswords and then that almost stopped overnight, she never picked up another book she never did another crossword'.*

He also remembered that the same was true of jigsaw puzzles.

AC *'And what about your relationship with Anne. Did it change the relationship?'*

TR *'Oh yes it did. We didn't have a relationship. It was being Anne's sort of dog's body.*

Recognition

I asked about recognition

TR *'She didn't know who I was at times. I remember at Homemead once I was there with my son and she said to me 'you go away I want to talk to your Dad' and sent me away you know to talk to my son'.*

I asked if Anne recognised other members of the family.

TR *Funnily enough she did recognise some people. She knew the grandchildren. You know her face used to light up when the grandchildren came.*

Communication since the onset of dementia

I asked about communication between himself and Anne.

TR *'Oh no communication wasn't OK. She never... she would talk but she wouldn't converse....and she used to call things all by the wrong name. Anything she liked no matter what it was she used to call whiskey. I remember being down the doctors surgery and she wanted to see the doctor very very disturbed, on edge, and she kept standing up saying 'I want whiskey! I want whiskey!' and people were sort of looking at her and thinking oh god we've got one here!' (chuckling).*

Thomas went on to describe the difficulties she had in communicating describing her talk as '*gobbledygook*'.

I asked if it was frustrating for either of them.

TR *'Well it was and I think it was so frustrating for her because she knew that I didn't understand if you know what I mean'.*

Does the carer think the person with dementia still knows what's going on? Do they have insight?

I asked if Anne ever had any lucid moments

Thomas said that she did occasionally and gave an example:

TR *'For example I'd take her out, walking down into town and she would say 'oh' I remember one time when she said 'Evans used to be here. You know now that was a remarkable thing because you know Evans had gone from the high street for a long time'.*

He said that the lucid moments were short lived.
I then asked if she had any lucid moments about her illness.

TR *'All she used to say was 'I want to die', continuously. I should imagine every time I went to Homemead every time I got her up during the day she'd say 'I want to die'*

He went on, *'she just hated her illness. And that's what seems so tragic about it, people know they've got it'.*

He spoke of how he felt Anne definitely knew she was ill. But that she never spoke about it.

What has it been like for Thomas?

I asked what it had been like for Thomas, caring for Anne.

TR *'I preferred to care for her than have other people in because they were just going through the motions they really were. I had carers in once and they came round to bath her three times a week and they would be here at nine o'clock cos I had to have her ready to go to Homemead.....And I'd be sitting here waiting for them at 1 o'clock! And in the end I said you know just don't bother. And they'd come in and in ten minutes they were gone again. So you know a real waste of time'.*

Summary of findings from visits

Well-being and ill-being profiles:

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

	Visit 1
Making wishes known	2
Initiating social contact	2
Warmth and affection	2
Self-respect	1
Being helpful	0
Humour	0
Bodily relaxation	0
Creative self-expression	1
Showing pleasure or enjoyment	1
Responding appropriately to others	1
Expressing appropriate emotions	2
Holding their own socially	1
Alertness, responsiveness	2
Being active	2
Being purposeful	1
Total	18

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

	Visit 1
Depression or despair	2
Intense anger	1
Grief	0
Anxiety	2
Fear	1
Boredom	0
Physical discomfort / pain	2
Bodily tension	2
Agitation	2
Apathy and withdrawal	1
Distress	2
Cultural isolation	2
Difficulty withstanding powerful others	2
Total	19

Anne showed moderate levels of well-being which reflect her warmth towards others. Not afraid to show her feelings or state her wishes she could be described as active on occasion. However, most of her behaviour showed strong indications of ill-being. In constant pain from her severe arthritis she also appeared desperate to lie down or go to bed. I felt this was also an indication of depression as Thomas described how she would not sleep but just lie there staring. Her ill-being also showed through in anxiety and agitation, particularly when away from home. Her anger with Thomas could also be observed when she dug her nails into his skin. Although Anne could show signs of well-being I felt that her signs of ill-being came across much more strongly.

The Behaviour rating scale for Psychological and Social problems (BPS)

	Cognition/44		Mood/28		Social contact/20		Total/140	
	TR	AC	TR	AC	TR	AC	TR	AC
Visit 1	26	29	9	24	14	18	69	97

TR = score as assessed by Thomas Reed

AC = score as assessed by the author

The agreement between Thomas and my scores on cognition and social contact is quite consistent. However, the large discrepancy on mood scores may highlight Thomas's lack of insight into Anne's predicament. His much lower score would suggest that he felt her to not have a great problem with ill-being, whereas the observations and indications would suggest otherwise, as my score reflects.

The Bristol Activities of Daily Living (BADLS)

	Total score/60	
	TR	AC
Visit 1	36	37

TR = score as assessed by Thomas Reed

AC = score as assessed by the author

Here again our score show good agreement on this scale.

Dementia Care Mapping

I managed to do an hour's mapping when I first arrived at the Reed's. However, this took an enormous amount of energy and as with Mr and Mrs Archer I made the decision that dementia care mapping would be too difficult on this visit. In particular Anne's distress was often plain to see and she would seek comfort from myself. I felt it would be unethical to merely observe and try to map if Anne sought comfort from me. When Anne was awake she was often in a WIB state of –1 or –3. Where possible she would go to bed, if allowed by Thomas. The results for the short mapping are presented in the visit notes (Appendix eight).

Malignant Social Psychology

A large proportion of Anne's interactions with Thomas would be classed as examples of malignant social psychology. They ranged from mild episodes of mockery when Thomas used to say pleasant things but in a sarcastic manner, for example when Anne had been very distressed in the car on the journey to her son's Thomas turned to her and said, *'Are you happy Anne? We're nearly there'.* The other and of the extreme saw very severe episodes where Thomas would treat Anne as an animal, telling her to *'Sit! Sit! Stay! Stay! Good dog! Good dog!'* Or to talk about his affair with one of her friends in her presence as if this would have no effect on her at all. I found these all very disturbing. Each of the examples are detailed in full in the appendix eight.

Positive Person Work

The examples of positive person work came from outside the home. Anne had a good rapport with the bus driver – she saw him as someone who would take her home, in her words to, *'make things good'*. He was very reassuring towards her when she became anxious, for example when he took a different route home in the bus.

Similarly her doctor acted in a reassuring and comforting manner towards her by touching her hand when speaking to her, sensing her distress. These two examples are signs of validation of Anne's emotions.

Carer support for intact abilities

When I first met Anne she could still feed herself, cutting up her food and then using a spoon. Thomas did not try to take over this task. After her heart attack she was in a general ward and the nurses didn't realise that Anne needed prompting or help to eat, hence Thomas realised that Anne was not eating. He travelled over to feed her at every mealtime after that. This shows that Thomas was aware of Anne's remaining abilities and allowed her to use them.

Carer validation of emotion

The examples of malignant social psychology are testament to how little validation Anne did receive. However, some examples can be seen under the positive person work heading.

Politeness strategies

I only witnessed one possible example of a politeness strategy by Anne when we arrived at the doctor's reception. She pointed to the pile of magazines saying to me, *'you can have a look'*.

Aspects of selfhood

Anne's self as a gregarious, fun-loving person who enjoyed the company of others had been affected by her dementia and the pain of her arthritis.

Despite Thomas's behaviour towards Anne and his assertion that she did not know what was going on, that, '*what people say goes over her head*', he still helped to retain an aspect of her self that was very important to her – her appearance. Taking care to apply her make-up each day he helped her to continue to look her best. Also dying her hair the colour she liked and painting her nails, Anne was always smartly presented when cared for by Thomas. When on respite her appearance changed as she did not have the help of Thomas. However, when he was not away he would visit her daily in Homemead, right up until her death, to help get her ready.

Perception and social death

I concluded early on in my observations that Thomas felt Anne was socially dead. His manner towards her, the numerous episodes of malignant social psychology, lead me to this belief. However this view did not sit neatly with all of his actions, for example helping her to look smart and nicely made-up each morning. In discussion with Thomas he said he wanted to know what '*they*' (people with dementia) thought about, or was it *'just blank'*. His curiosity suggests the possibility for his mind being not completely made up. This was further supported by his surprise at Anne's lucid moments. However, these inconsistent views did not seem to change his behaviour towards her.

Longitudinal profile

By the time of my first visit Anne's verbal ability had declined, and she would often use the word 'whiskey' in place of a word she could not bring to mind. This level of speech remained constant throughout the study. What altered was Anne's well/ill-being. Her high levels of ill-being noted at my first visit remained during subsequent observations at the day centre but lifted on my last visit when she was in residential care following her hip operation. This lift in mood was a surprise considering the high levels of malignant social psychology she endured from Thomas. Whether this lift in well-being was due to the removal of physical pain cannot be concluded since she had now also moved away from home. Her relationship with Thomas appeared a paradox: Having now taken a lover, and now that Anne was in residential care, one might expect him to concentrate on his new life. However, he visited her daily to feed and dress her and to apply her make-up, thus one aspect of their love endured.

Résumé

Anne showed for the most part a high level of ill-being, wanting to spend her time in bed. However, she showed some signs of well-being during her last months in a residential home after her hip operation. She was no longer in physical pain. Thomas showed a belief in social death, but also wondered what lucid moments meant. His behaviour was in line with his belief of social death in terms of the malignant social psychology, however, he applied make-up daily to Anne, knowing how she liked to look her best. This behaviour does not sit comfortably with his belief, and shows a contradictory side.

Anne's case study does not read as a happy account. If one key aspect can be taken from her situation it must be the devastating effect of malignant social psychology on well-being.

Mr and Mrs Jackson

Background

Jim (89) and Eileen (82) Jackson have been married for almost 60 years and live in Chichester. She has had probable Alzheimer's Disease for 14 years. Her illness had a gradual onset with confusion and paranoia featuring early on. When I first met her she had very limited speech, and required Jim's care on a full-time basis.

My immediate impression of Eileen and Jim was of a couple still very much in love. When sitting together they would usually touch, and frequently joke together. Their jokes or teasing often ended with a hug or clasping of hands and gazing into each others eyes fondly.

They have lived in their house in Chichester for the past 40 years, have several neighbours who are also elderly and have also lived there many years, and they all look out for one another. They have friends with whom they go out for a meal at the local pub each Friday. This has been such a long standing tradition that the landlord has affectionately named them 'The Friday Club'. Jim sees this as important for Eileen as it *'gives her a break'.*

They have one daughter, who lives a couple of hours drive away, but their granddaughter and her husband live nearer, and often visit with their baby boy. Eileen enjoys playing with, and singing to, her great grandson.

Jim felt that research into dementia should be carried out *'at grass roots level'* and hence was very keen to take part in this study. He said that he felt it was important to consider the experiences of people living in this situation rather than, say, what the doctors want. He extended this view to the work of the Alzheimer's Society, which, although he supported and found useful, felt that *'you fit in with them rather than they work round you'.*

The Jacksons were recruited with the help of the local Alzheimer's society. Jim, a proud man who didn't want help in caring for Eileen, did not want to send her to a day centre. However, after my first stay he realised that he had enjoyed speaking to someone and felt he needed more time to himself. As a result he asked if Eileen could attend Homemead once a week. This highlighted the effect that this kind of research could have on those researched. It is clear that to say participant observation is merely observing is not true. By joining the group to be observed you necessarily change it. Whilst I was pleased for Jim in this respect I was concerned for Eileen. However, my worries were unfounded as I was able to observe her at Homemead enjoying her time their. She fast became a favourite of the staff and would be seen singing and dancing with them.

I visited the Jacksons three times and stayed with them for three days on each occasion. Since finishing the study I have been to visit Jim as he now lives alone having taken the decision that Eileen would be better off staying at Homemead full time. Selfless in this decision as in others he felt very worried about what might happen to Eileen if anything happened to him. No longer in the good health he earlier enjoyed, this concerned him greatly. A place became available at Homemead and staff asked him if he would like Eileen to have it. He was given just over 24 hours to make *'the hardest decision of his life'*. I had arranged to interview Jim just after this happened and made the decision to abandon the interview, instead visiting Jim to talk with him. He did not mention the interview – no doubt the very last thing on his mind. I later saw Eileen at Homemead, again in good spirits and in a high state of well-being, leading a morning sing-song.

Visit 1, April 2001

I arrived on a Sunday morning, as arranged, and had a coffee whilst we watched the London marathon on television. Eileen seemed to be enjoying the race, saying *'look at all those people!'* Jim made lunch, cutting up some of Eileen's ham so that she could eat unaided.

When I'd visited families for a day in my pilot study I felt happy to take my own food (as I am a vegetarian) and the families were happy to accommodate my diet (and both were women cooking). However, I felt particularly awkward about mentioning this to Mr and Mrs Jackson as I was so delighted when they agreed to take part and let me stay. I felt that a man in his eighties looking after his wife might find catering for a vegetarian difficult. I know my own father can get stressed when cooking for more than just the two of us. I also felt that to some extent 'when in Rome…'. I wrestled with my conscience over this one, considering eating meat for the duration of the stay so as not to change any of their eating habits. However, I was also concerned as to what effect eating meat after a gap of 16 years would do to my body! I could have become a liability during the study! So I decided to broach the subject with Mr Jackson and bring some of my own food. He was fine about this, and dished up vegetables for me so that I could just add my own quiche etc. He had been a cook in the Air Force during the war and was used to cooking.

Jim appeared to be a very patient and considerate carer. His view of caring for someone with dementia was that you don't know what is going inside their head so you have to keep an open mind. He said that in his view *'the best thing is to keep them happy and then half the battle's won'.* Jim now has to do most of the domestic chores as well as Eileen's personal care. He doesn't find this a problem and used to cook in the Air Force during the war. He spoke a lot about his war memories during my stay, and seems to have enjoyed his past life and is reasonably content, or at least resigned to, his present one. Although I did not feel that Jim showed any signs of ill-being himself during my stay, he did say, however, that caring for Eileen can be *'boring'* at times, and that he had enjoyed my stay as it was nice to have someone to chat to. He also told me that his daughter had wanted to arrange a party for their Diamond Wedding anniversary, but that he had told her not to because, *'there's no point'*. He did not appear to convey any negative feeling he had about his situation to his caring for Eileen, however.

I felt I settled into this, my first long stay with a couple, quite quickly and whilst I was reading the Sunday paper after lunch both Eileen and Jim slept for about 45 minutes. I felt this was an indication that they were comfortable with my presence at this time – rather than being on 'best behaviour'.

On Sunday evening I was able to observe Eileen in a high state of well-being as she sung along to hymns on Songs of Praise. She used to sing in a group and clearly still very much enjoyed this.

During breakfast on the second morning at the Jackson's Jim asked me if I had noticed anything different about my tea. It turned out that he used decaffeinated tea and coffee. This explained the dull headache I had developed during the latter part of the first day which hadn't shifted overnight. I had put this down to the stress of concentrating on my observations whereas I was actually suffering from caffeine withdrawal! I was undergoing a three day detox. This highlighted my 'plight' as a researcher in this kind of in-depth research, cut off from my usual world and facilities.

Later that morning we went into Chichester for a walk around the shops and a coffee. I was able to observe Eileen outside the home, where she seemed happy to look around, secure with Jim holding her hand. We also bumped into some neighbours who Eileen seemed to recognise and was happy to meet. We returned home for lunch followed by an afternoon sitting quietly watching some television. Jim also spent some time talking to me about his past and showing me photographs. Eileen seemed content to sit next to Jim whilst he talked, and he stroked her foot throughout.

On the third and final day we went to the local Alzheimer's Society lunch, where again I was able to observe Eileen in a different social context. She appeared very secure in her relationship with Jim. During my stay I was able to see her reaction to Jim talking to or giving attention to other women, for example, at the Alzheimer's Society lunch Jim spent some time talking to his friend Hazel. Here Eileen showed no signs of anxiety, at one point turned to me and said *'he's having a good chat!'* At the Alzheimer's lunch he told his friends how much he had enjoyed my stay as it had been a *'break'* for him, *'to have someone to talk to'*. When I left later that day he told me again how much he had enjoyed my stay.

I very much enjoyed chatting to Jim – he has a very positive view of life which I found infectious. When I came away I felt in a strange way energised about my own life. We had spoken about my love of London and he had encouraged me to enjoy the local area down here while I could. He was of the opinion that we only regret things that we don't do in life rather than things we do. He said he had always wanted to go to Canada, and had hoped that they would go into their retirement, but that her illness had prevented this – this was something he regretted.

Visit to Mr and Mrs Reed, July 2001

During this visit I was able to observe Jim and Eileen as they were on the same Alzheimer's society outing to the manor house on the second day of my visit and then again at Homemead on my final day.

At the manor house, in contrast to Anne Reed, Eileen was in a high state of well-being. Clearly excited about the outing she sat holding Jim's hand on the coach and smiling. At the house they wandered around together hand in hand, both seeming to be very happy.

At Homemead the next day I observed Eileen arriving at the day centre. She was happy to be greeted by the staff and enjoyed a cup of tea on arrival saying *'oh thank you very much!'* when a member of staff brought one to her. She joined in with the weaving activity and was very engrossed in making her section of fabric. Throughout the day she remained in a WIB state of +1 moving to +3 on interaction with staff. She enjoyed the bus ride home and said she'd had a lovely time.

Visit 2, October 2001

I arrived at the Jackson's on Sunday morning. This time I had remembered that they only drink decaffeinated tea and coffee and had brought some caffeine tablets with me so I wouldn't get withdrawal headaches.

I didn't notice any great change in Eileen since my last visit six months ago, but Jim said that she sometimes wanders off and gets lost so he has put locks on the front and kitchen doors to prevent her getting out if he's in the garden. He also said he has to help her go to the toilet now.

Since my last visit he had decided that it might be good for Eileen to go to the day centre one day a week, to *'give her a change of scenery'* and to meet other people, and so she had begun to go to Homemead on Tuesdays. I was able to observe her there at this visit.

As before, the first day of the visit Jim spent a lot of time chatting to me and showing me photographs. However, Eileen joins in at times and clearly was able to follow the conversation on occasions, spending much of the time in a WIB state of +1. However, in the evening there was a special edition of Songs of Praise and Eileen sung along moving into well being states of +3 and +5. On occasions during my stay Eileen would sing and move into a higher state of well-being.

Both the first two days of my visit were spent at the Jackson's own home, popping out briefly in Jim's car so he could deliver some local newsletters. We would have walked on another day but the weather was dreadful. Jim also expressed concern about how much longer Eileen would be able to walk daily, as she was finding it a little more difficult.

His worry about the future showed again later when he told me that he was worried what would happen to Eileen if anything happened to him. He had raised this worry with the Alzheimer's society and they had been looking into what could be done so as to reassure him.

The final day of my visit was spent with Eileen at Homemead. Here I was able to observe her in a different setting. She was just as relaxed in this setting as she was at home, turning to me on two occasions saying, *'it's really nice here isn't it?'* She was also helpful towards other clients less able than herself, showing one lady how to roll a dice during a game and then encouraging her *'that's right, that's the way'.* Clearly one of the staff's favourites, Eileen joined in with singing and dancing and had a thoroughly good day.

Visit to Mr and Mrs Archer, November 2001

During my stay with Mr and Mrs Archer I was able to observe Eileen at Homemead. She was happy to help out with some pastry making for jam tarts. In the afternoon Eileen sung alone to some old tunes played on the tape and danced the okey-kokey, varying between a WIB state of +3 and +5 at these times. However, she was not engaged during the newspaper reading by staff.

She showed a politeness strategy by offering one of the other clients her seat at one stage.

Visit 3, May 2002

At this third and final visit I found Eileen to have gone slightly downhill, for example, she required Jim's help much more to find the toilet as she seemed more lost in her own surroundings. She had also begun to sing all the time, including when waking at night. Jim said that this *'drives you round the bend',* although I didn't feel he ever let that show to Eileen. Sometimes he would initiate a different song for her to sing. I felt that his outlook on life in general may have helped him to cope with something he found very annoying, without getting angry. I found Jim to be one of world's optimists, who can make the best of every situation they find themselves in. For example, as he spends much time sitting in his chair with Eileen looking out to the garden he watches the blue tits nesting and other birds feeding and then reads about their habitat and lifestyles. After each visit I have come away energised by Jim's enthusiasm for even the smallest of things. I feel he doesn't have a depressive bone in his body and admire that trait.

When I arrived on Saturday morning I met Ivy, Eileen's older sister, who often visited on Saturdays. Ivy had looked after Eileen when they were children as their mother had died when they were young. I suspected that Jim and Ivy didn't always see eye to eye as they both had 'little asides' to me about each other throughout the day. Ivy explaining that she *'didn't like to interfere'* with the care of Eileen as Jim was very independent. Ivy was a very different character to Jim, very serious and often gloomy.

Jim and I went out to get fish and chips for lunch and on returning found Eileen with her coat on in the hall. Ivy explained that she had tried to get her to take her coat off, and in an aside to me said that Eileen had punched her. I was surprised as I had never witnessed an aggressive side to Eileen.

Ivy would often ask Eileen if she wanted to go to the toilet, but she always replied *'no'*. However at one point she whispered to Jim that she wanted to go to the toilet, clearly not wanting to be helped by Ivy, and perhaps indicating a sense of self respect intact. In fact when Ivy tried to 'fuss' over Eileen, Eileen would sometimes look towards me and make faces and we'd laugh quietly.

Jim drove us all to Ivy's and Eileen spotted a beautiful field of colour, exclaiming *'look at that yellow!'* When alone with me Ivy told me that a little while ago Eileen had gone into Homemead on respite care for a couple of weeks whilst Jim visited his brother. Ivy had visited and was beckoned into the toilet by Eileen on the pretence that she wanted some help. When in the cubicle Eileen said, *'You've got to get me out of here, they wont let me out'.* I felt this incidence indicated her depth of understanding of her situation.

On Sunday Jim, Eileen and myself walked to the local shops. Eileen had had a sore knee yesterday but told me that it was *'better than it was'*, indicating that she remembered that it had been sorer the day before. When we returned Jim put the television on as there was a programme containing hymns. However, Eileen was not as settled as she used to be during religious programmes and spent the rest of the morning walking between the lounge and the front door, wanting to go out. Jim took her round the garden later to try and settle her.

In the afternoon we all sat and watched television and then Eileen slept cuddled up to Jim whilst a football match was showing. After tea Eileen became restless again, asking Jim at least 24 times in one hour, *'what am I going to do Jim?'* and he replying patiently, *'nothing, you've got nothing to do'.* She was even restless during Songs of Praise, pausing only to say the Lord's Prayer along with the presenter.

My final day was spent in a similar way, sitting down whilst Eileen paced up and down, and sung the same line from a song over and over again. I counted 20 repeats of the same 8 lines in half an hour. I also noticed that as I walked round their house I was shuffling in the same manner as they did.

Mr Jackson and Homemead, April 2003

I had arranged to interview Jim but shortly afterwards Eileen had been taken into Homemead on a permanent basis. Hence I made the decision to abandon the interview, instead visiting Jim to talk with him. He did not mention the interview – no doubt the very last thing on his mind. Later that day I saw Eileen at Homemead, again in good spirits and in a high state of well-being, leading a morning sing-song on one of the wards, which was facilitated on a weekly basis by one of the resident's relatives.

Aspects from the interview schedule

How it began

When I first met Jim he described how 12 years ago Eileen had begun to get confused, often losing things and also becoming paranoid, feeling people were out to get her. She was diagnosed with probable Alzheimer's Disease.

Jim's knowledge of dementia at that time

I do not know if Jim had any knowledge of dementia then but he sought out information, joining the Alzheimer's Society and attending local events with Eileen.

How does the carer see their relative's quality of life?

On one of my visits Jim talked to me about how Eileen is now *'living in a void, a vacuum'*. He said that he has to do his best to fill that vacuum, adding that he thought it must be terrible to be that person living in a vacuum, being able to move around but not to do anything any more. In other words he sees people with dementia as having diminishing abilities but still feeling emotions, and further sees the carer's role as helping to fill the '*vacuum*' by initiating activities and helping them to pass the time.

Communication since the onset of dementia

Eileen had limited speech when I first met her, but they communicated easily together, often sharing 'private jokes' which clearly were from years of being together.

Eileen recognised Jim's difficulty with hearing and often repeated things to help him understand.

Recognition

Eileen appeared to recognise Jim at all visits. She also pointed out Ivy in her garden on my last visit saying, *'that's old Ivy'.*

Ivy spoke of Eileen's time on respite care for two weeks and said that she didn't recognise Jim when she came out. However, this was prior to my third visit when she clearly recognised him.

Does the carer think the person with dementia still knows what's going on? Do they have insight?

Jim often remarked that he was amazed at some of Eileen's lucid moments, such as recognising the coach that they had been on the day after a trip out. He was also amazed at her ability to remember whole songs and prayers.

I would say that Jim's view was that he didn't know what the person with dementia thought, but that they clearly still had feelings and the carer's role was to keep them in a positive state of mind.

Summary of findings from visits

Well-being and ill-being profiles:

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

	Visit 1	Visit 2	Visit 3
Making wishes known	2	2	2
Initiating social contact	1	2	1
Warmth and affection	2	2	2
Self-respect	1	1	1
Being helpful	2	2	2
Humour	2	2	2
Bodily relaxation	2	2	2
Creative self-expression	2	2	2
Showing pleasure or enjoyment	2	2	2
Responding appropriately to others	1	1	0
Expressing appropriate emotions	1	1	1
Holding their own socially	1	1	1
Alertness, responsiveness	1	1	1
Being active	2	2	2
Being purposeful	1	1	1
Total	23	24	22

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

	Visit 1	Visit 2	Visit 3
Depression or despair	1	0	0
Intense anger	0	0	0
Grief	1	0	0
Anxiety	1	1	1
Fear	0	0	0
Boredom	1	1	1
Physical discomfort / pain	0	0	1
Bodily tension	0	0	0
Agitation	1	1	2
Apathy and withdrawal	1	0	0
Distress	0	0	0
Cultural isolation	1	1	0
Difficulty withstanding powerful others	0	0	0
Total	7	4	5

Eileen's consistently high well-being scores reflect her continued enjoyment for activities and also, importantly, her excellent relationship with Jim. Still very much in love, despite Eileen's failing powers of speech they still communicated by touch and gaze, often holding each others' hand and looking into each others' eyes. Her consistently low ill-being score also corroborates this, with one area for ill-being being her restlessness in the home, perhaps searching for work. This restlessness was not seen in a different context, that of the day centre, where Eileen would become engaged in activities.

The Behaviour rating scale for Psychological and Social problems (BPS)

	Cognition/44		Mood/28		Social contact/20		Total/140	
	JJ	AC	JJ	AC	JJ	AC	JJ	AC
Visit 1	41	35	4	0	13	7	70	49
Visit 2	41	29	4	0	11	8	69	42
Visit 3	38	33	4	0	13	8	67	52

JJ = score as assessed by Jim Jackson
AC = score as assessed by the author

Scores show continuity across time for both scorers despite the difference in level. I have assessed Eileen's cognitive abilities as less impaired than Jim. Similarly for social contact I have assessed Eileen as having more interaction.

The Bristol Activities of Daily Living (BADLS)

	Total score/60	
	JJ	AC
Visit 1	38	29
Visit 2	44	33
Visit 3	44	35

JJ = score as assessed by Jim Jackson
AC = score as assessed by the author

Scores show a decline across time by both scorers. I saw the decline as Eileen's increased confusion about where the bathroom was in her own home, and also the increasing communication difficulty with others. For Jim the decline in orientation around her own home was seen as more severe in level.

Dementia Care Mapping (DCM)

I managed to carry out dementia care mapping at each of the three visits, and a fairly similar pattern emerged each time. Eileen spent much of her time in a WIB state of +1, but moving to +3 and +5 at times during the day. I only noted a couple of episodes in –1 over the whole total of the visits. This is reflected in the graphs of well-being scores for the visits presented overleaf.

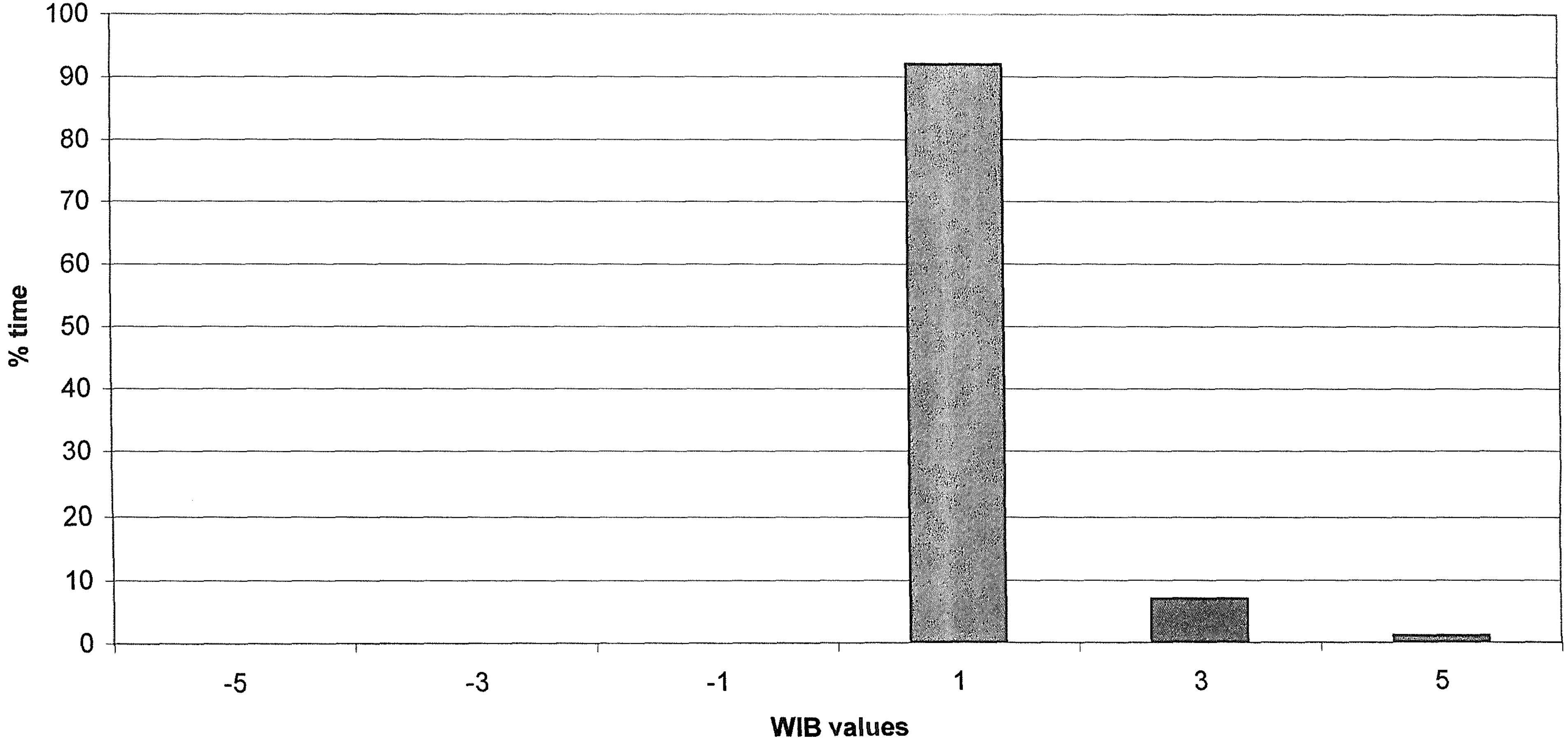
On my first and second visits I was able to map for approx 12 hours over the three days, and at my final visit approx 5.5 hours over two days, the final day I did no mapping.

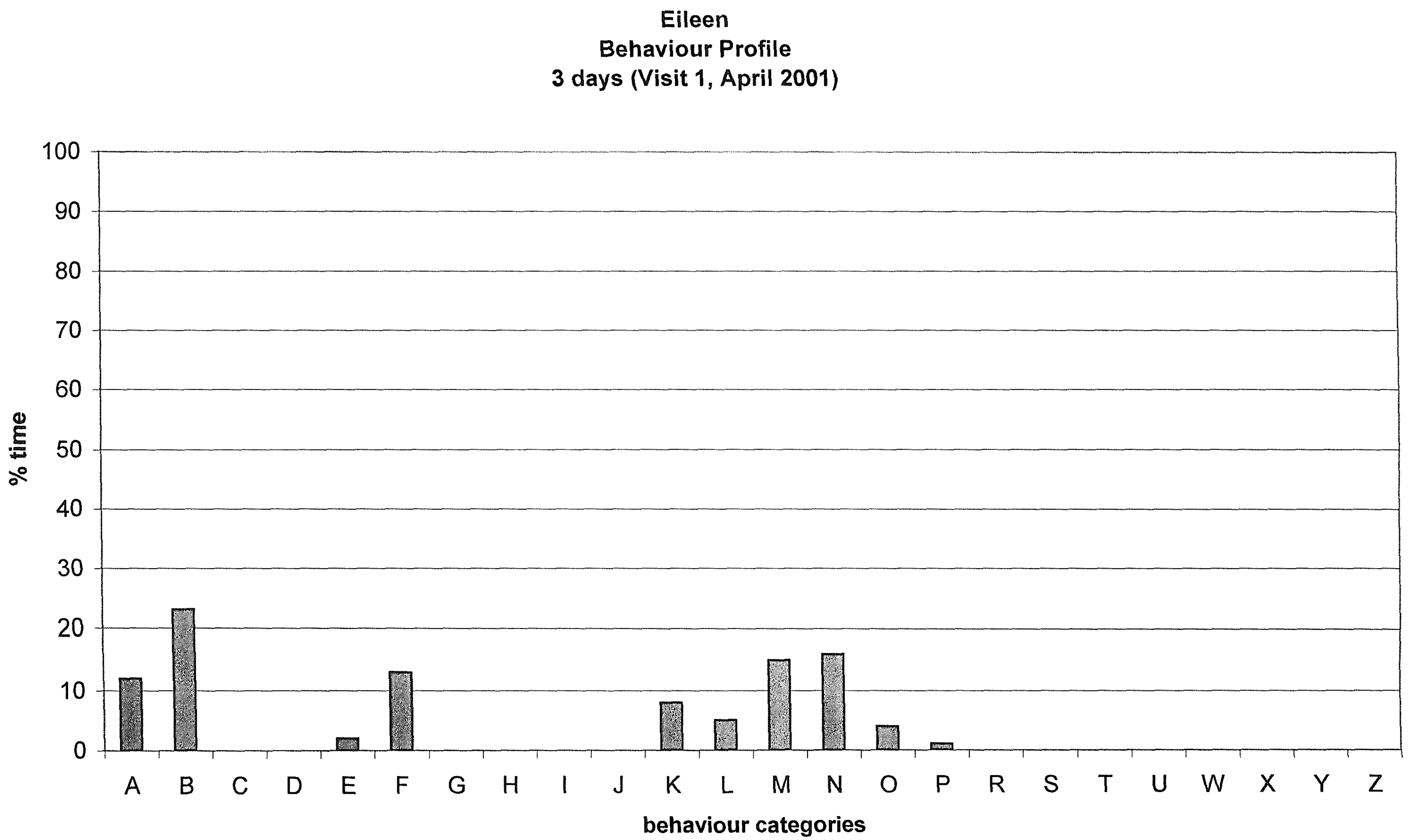
The behaviour profiles presented overleaf show similar patterns for each visit with Eileen's main activity showing as watching the television, or in work related activities between the kitchen and lounge, where she would spend much time going to and from. On the first visit I had noted this as K (walking) or L (work), but on the second visit I felt this was taking a more repetitive manner and coded it as W (repetitive self-stimulation). What does stand out is that other than singing (which Eileen did enjoy), she did not engage in any handicrafts, games or similar activities in her own home. Yet I observed Eileen very engaged in such activities at Homemead, showing that she had the ability but this was not carried out at home.

Eileen also spent some time sleeping in the afternoons, and although this went slightly over the ‘appropriate sleep’ amount of one and a half hours the associated WIB value was not degraded as she was in close contact with Jim, who was cuddling her.

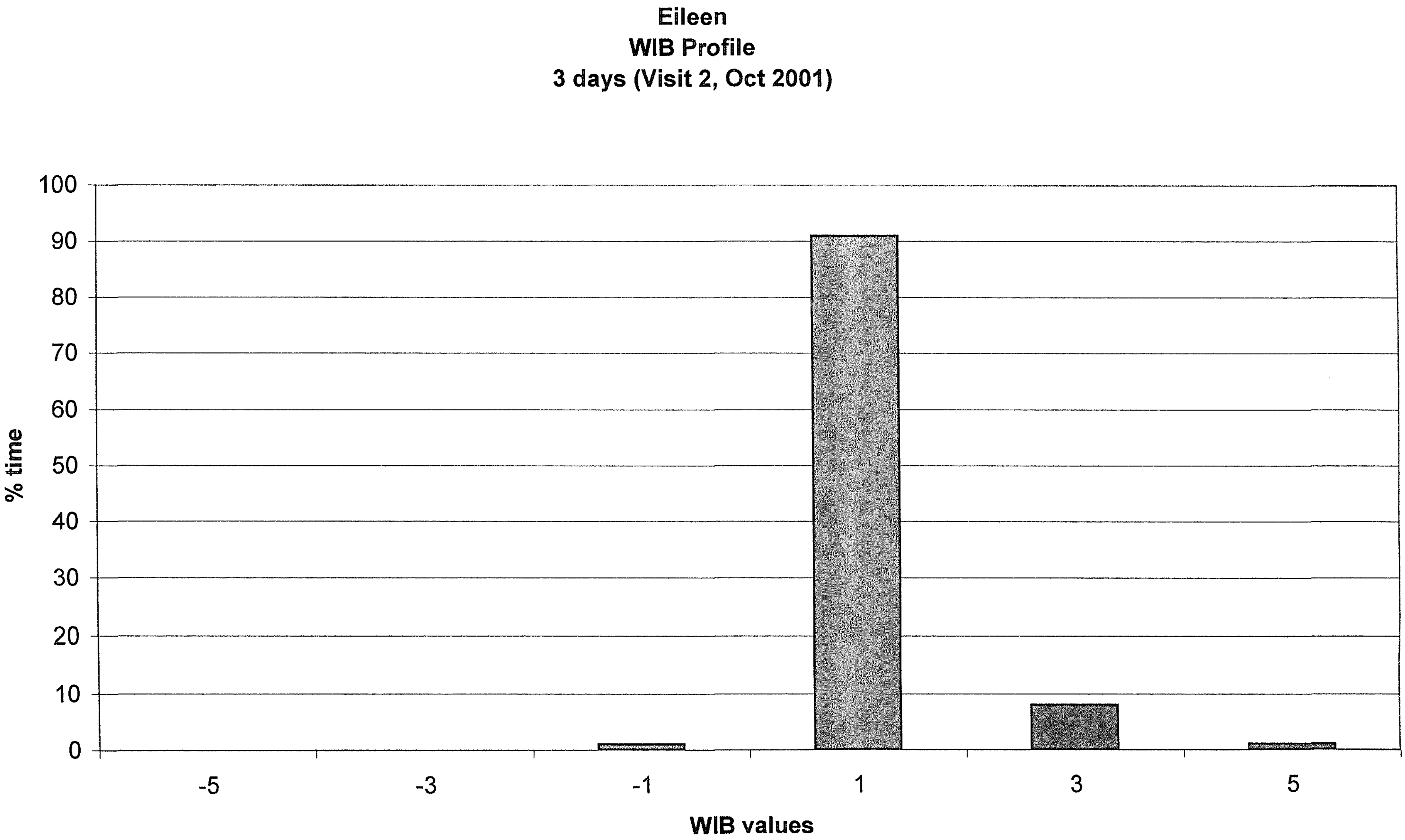
Summary WIB profile and behaviour category graphs for the visits are presented overleaf. Day by day graphs for each visit are presented in appendix nine.

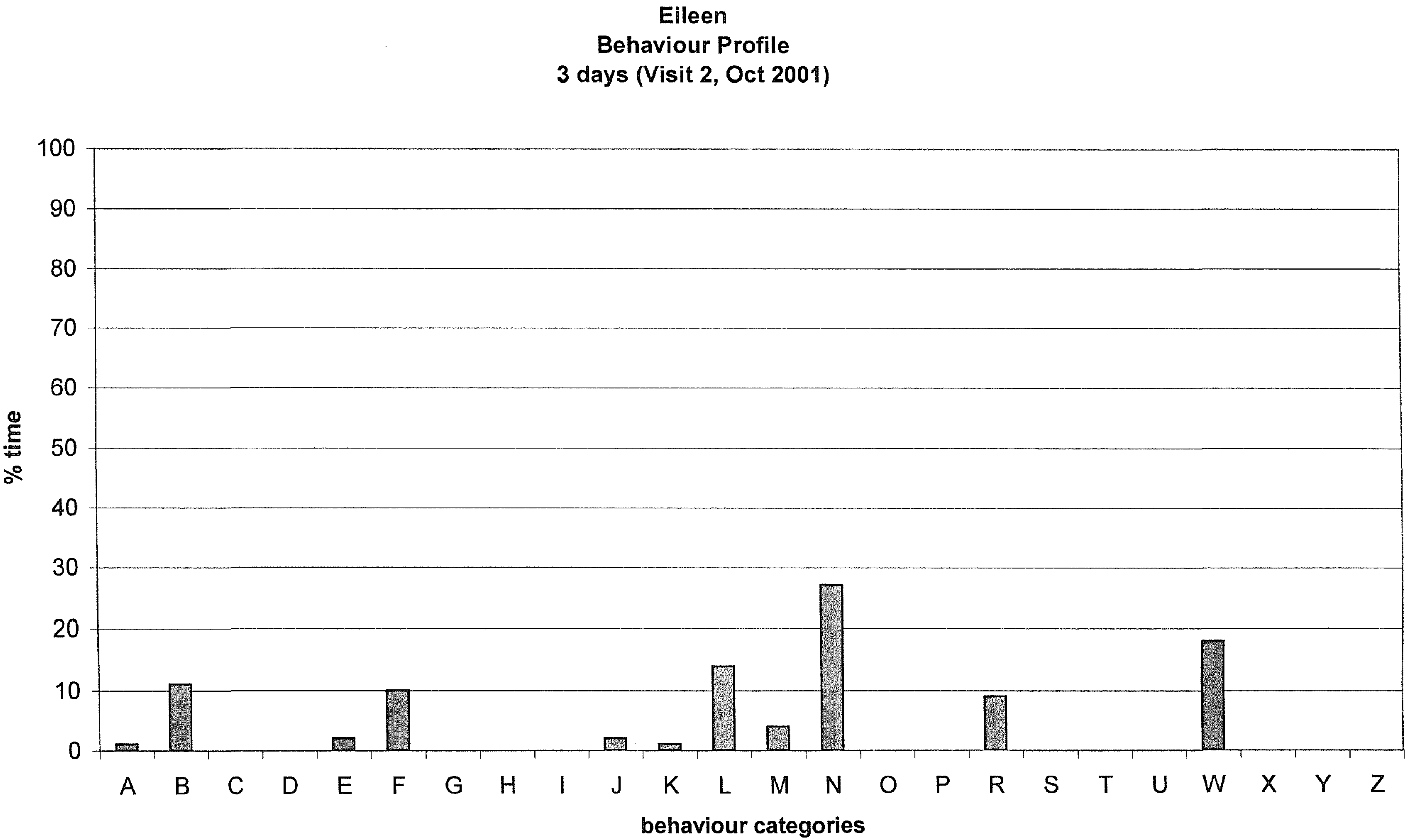
Eileen
WIB Profile
3 days (Visit 1, April 2001)





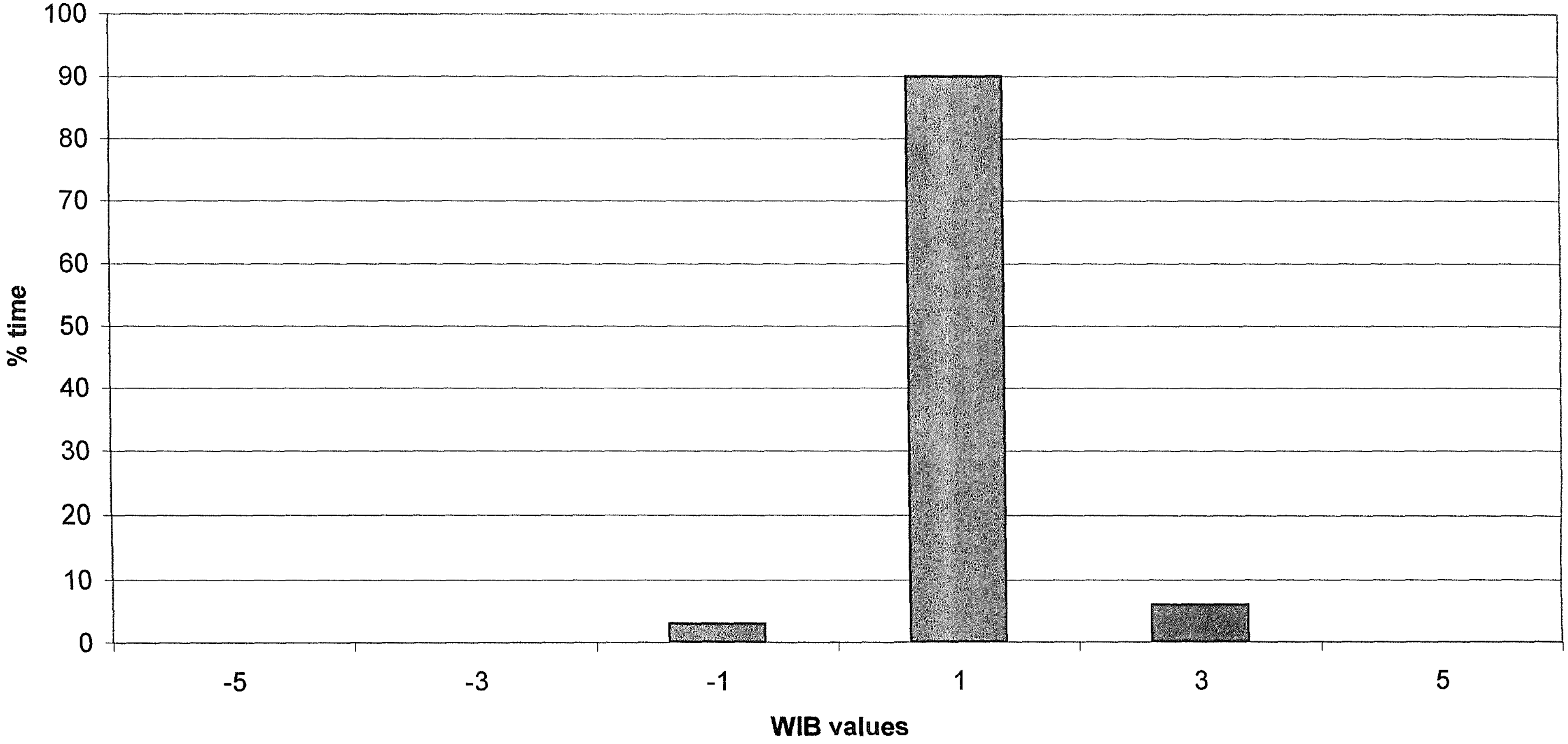
Eileen
Behaviour Profile
3 days (Visit 1, April 2001)

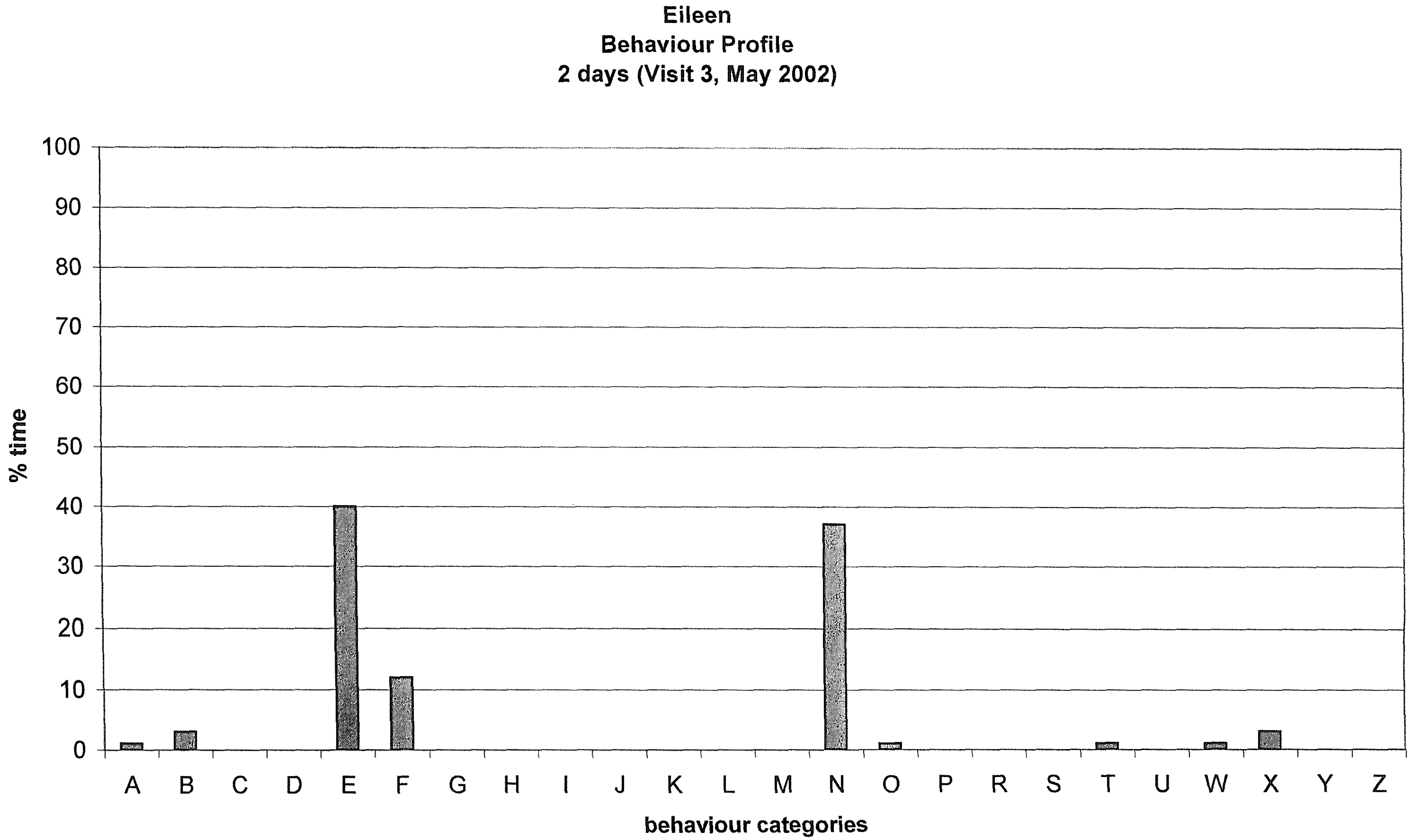

Eileen
WIB Profile
3 days (Visit 2, Oct 2001)
% time
100
90
80
70
60
50
40
30
20
10
0
-5
-3
-1
1
3
5
WIB values



Eileen
Behaviour Profile
3 days (Visit 2, Oct 2001)

Eileen
WIB Profile
2 days (Visit 3, May 2002)





Eileen
Behaviour Profile
2 days (Visit 3, May 2002)

Malignant Social Psychology

During my stays with the Jackson's the only elements of malignant social psychology were carried out by people other than Jim. For example, at the Alzheimer's society lunch on my first visit no-one on Eileen and Jim's table talked directly to Eileen (ignoring). Later that evening a neighbour popped in to see Eileen and Jim and on not being able to think of a word said, *'oh I'm getting like Eileen!'* in Eileen's presence (mockery). On my second visit I accompanied Eileen to Homemead where I observed an example of disparagement from a staff member to the group of clients who were around her.

However, on my final visit when observing Jim and Eileen's repeated pattern of questioning and answer, I decided that this behaviour was an element of withholding. When Eileen walked to and from the kitchen she would ask *'what have I got to do Jimmy?'* and he would reply, *'nothing, there's nothing you've got to do'*. Although unintentional (as Kitwood says malignant social psychology often is), Jim may be failing to help Eileen meet an evident need for activity in the home. This again shows the value of visits over time and of increased length, as I had not originally framed this interaction in the same way. In addition, being able to observe Eileen in the different context of the day centre enabled me to see that she could become very engaged with activities.

Positive Person Work

Examples of positive person work that I saw at each visit were: timalation, as Jim would often sit stroking Eileen's hand or foot; and play, as Jim and Eileen would often joke with each other and Eileen's WIB value would rise to +3 or +5. Also facilitation and collaboration in the way that Jim and Eileen worked together in personal care tasks, and helping to cut up her food so she would be able to feed herself.

At the day centre I observed an example of positive person work carried out by Eileen herself, and this helps to illustrate her high level of well-being. During a game one afternoon the lady sitting next to Eileen couldn't manage to roll the dice. Eileen showed her how and when she started to do so on her own gave encouragement saying, *'that's right, that's the way'.*

Carer support for intact abilities

Eileen still had many abilities intact, such as being able to eat unaided, but sometimes requiring the food to be made more manageable, such as cutting into smaller pieces or meat being removed from the bone. Here Jim would always check before cutting and only help if Eileen asked. Similarly with getting dressed, washing and other personal care Jim would help Eileen but not take over. He would facilitate her ability to dress and they would be working together, often joking as they did.

Carer validation of emotion

Although Jim didn't find Eileen work in the home when she asked, *'what have I got to do now Jimmy?'*, he did recognise that she felt slightly anxious and would reassure her saying, *'nothing duck, come and sit down with me'.*
When Jim noticed Eileen was becoming restless he would take her for a walk round their garden, holding her hand.

Similarly with positive emotions Jim would recognise Eileen's love of singing (although it sometimes drove him mad!) and he would encourage her and look affectionately at her. This affection would also show when he cuddled her as she slept next to him on the sofa.

Politeness strategies

The main example of politeness that was seen at both home and the day centre was Eileen's delight at someone bringing her a cup of tea. She would exclaim, *'oh thank you!'* and beam.

Jim was hard of hearing and Eileen recognised this, repeating what she had said if he looked confused or said, *'what?'* Considering her limited speech, this was rather noticeable.

Aspects of selfhood

Eileen's self as wife is still preserved and nurtured by Jim's care. Still holding hands and cuddling, she seemed very secure in her relationship with Jim. During my visits I was able to see Eileen's reaction to Jim talking to or giving attention to other women, for example, at the Alzheimer's Society lunch Jim spent some time talking to his friend Hazel, and when their next door neighbour visited Jim walked her home afterwards as it was dark. In both cases Eileen showed no signs of anxiety.

Eileen's self as friend was also still evident with her membership of the 'Friday Club' where eight old friends would meet down the local pub for lunch and a chat.
One aspect which may not be thriving is Eileen's self as homemaker. Now that Jim has taken over the household chores she appears to be looking for things to tidy and straighten. However, she always seemed pleased if Jim said he would do the washing up.

Perception and social death

Jim seemed to feel that *'you don't know what's going on in their head so you have to keep an open mind'.* His view was formed by witnessing lucid moments and also his amazement at Eileen's continued ability to sing and remember the words.

He once described Eileen as *'living in a void, a vacuum'*, and saw the carer's role as filling the vacuum, and keeping the person in a positive frame of mind, as he felt it must be terrible to be living in the vacuum. This suggests that he believes that people with dementia still have very real emotions and that in this sense are not socially dead. The fact that he still takes Eileen to the Friday Club also suggests that he does not view her as socially dead, indeed as do most of their interactions together.

Longitudinal profile

Eileen's verbally ability was limited when I first met her. She would use short phrases, but never long sentences, to communicate. This ability declined further over the course of my visits. However, her ability to sing songs, remembering the words, remained throughout. She would often sing along to hymns or to herself. Eileen was still able to walk unaided, although a little uncertainly, throughout my visits. She remained orientated within her home until my final visit, when she appeared to be a little unsure of where the toilet was, asking Jim for directions. Her well-being levels remained consistently high throughout and were paralleled by her consistently low scores for ill-being. Their marriage had been a long and happy one and Jim now took great care of Eileen, helping her to retain personhood and well-being through positive interactions and love.

Résumé

Eileen showed consistently good levels of well-being with episodes of very high well-being, particularly when singing. Latterly she had become more agitated when at home, perhaps looking for work. She was not agitated in the day centre and engaged in activities. Jim did not believe Eileen to be socially dead, instead saw it as his duty to help facilitate this aspect of her life. His behaviour was also consistent with this view.

The fact that Eileen had remained at home for over 12 years since her diagnosis is, in my view, down to Jim's excellent care. I observed the positive effect of a happy marriage, coupled with Jim's good use of positive person work, on Eileen's well-being.

Chapter Seven

Conclusion

Introduction

This final chapter sets out the key findings of this study, beginning with a review of all aspects of the methodology used. Firstly the role of the case study as an important, but often neglected, method of inquiry is highlighted. Then participant observation is put under the spotlight and its advantages and limitations exposed. In particular the reader is advised of the difficulties of this type of method for the researcher, as well as the usual dilemmas of validity and reliability. Attention is then turned to the different measures used to examine well/ill-being, and their suitability assessed. In particular the role of Dementia Care Mapping within a community setting is detailed. Finally within this methodology section the measures of social death, derived from the thematic analyses of biographies are examined.

The chapter then considers what this thesis adds to the existing literature on psychosocial aspects of dementia. Here the importance of this study in furthering knowledge about the day-to-day lives of people with dementia and their carers is highlighted. Then the contribution this study plays in reiterating and adding to the role of psychosocial aspects is discussed. Finally the input this study has made to furthering the knowledge on social death is detailed.

The final section of this chapter looks at areas singled out as important for future work, namely the importance of studying the different behaviours made by people with dementia in different contexts and settings and also lucid moments.

Methodology

Case studies

As chapter two explained, the complex interplay of biology and psychology in the field of dementia has not been fully understood. Psychosocial aspects have been shown to have a key role in this equation in the literature review but these facets of a person's life are both complex and multifactoral, posing methodological dilemmas for the researcher. This study has shown that the case study provides a good methodological strategy for approaching complex topics such as this. Sabat's (2001) carefully constructed case studies are also testament to this. As well as considering the many aspects of a person's life which may have a bearing on well-being, a case study method also provides a means of corroborating data and assumptions. For this reason the case study is recommended to researchers interested in furthering this field. Readers are asked to consider if the depth of detail and the extent of the findings presented in this thesis could have been elicited using short interviews and questionnaires. The variety of means of data collection employed within the case studies were crucial in drawing together a fuller picture of the couples' lives.

On a broader note, as chapter three explained, the case study has been less than popular in current day research in psychology. However, this research has helped to lend support to the argument for using case studies. This study used case studies to explore pre-determined concepts and theory, surrounding the importance of good interactions for the maintenance of well-being and personhood. But also they were used to develop and explore further the involvement of social death in the style of the carer's care, demonstrating some of the uses of case studies as detailed by (McAdams & West 1997).

Participant observation

The ideal method would have been to be a fly on the wall of the couples on both good and bad days. The realistic way of getting to this ideal was sought and participant observation used. The role of 'observer as participant' was chosen so that the family would be active in carrying out their usual day-to day activities and the researcher would join in but take a passive role in decision making, allowing them to observe.

Extended visits of up to three days were used and the visits repeated, where possible, over a two and a half year time span. By making extended visits I was able to see the couple in a variety of different settings, for example, at home, at a day centre. In addition this allowed me to observe the behaviour of the person with dementia in the presence of different people, and hence different caring styles. This was thought to be important since Sabat (2001) points out that if a person with dementia shows different levels of well-being in different settings it could be due to the effect of malignant social psychology. Pages 251 and 252 of this chapter explores how this aspect of observation helped to illuminate my own case studies.

Reactivity

Many would argue that the presence of a researcher would necessarily change the dynamics and that it would not be possible to see a 'true' picture of day-to-day life. However, although a fly on the wall would be the ideal scenario, participants observation offers a realistic solution. It may be true that reactivity would be present in shorter visits, indeed I have observed this myself during my MSc (Carr 1999). However, longer visits would help to minimise this and as the couples became more used to my presence it was hoped that more usual patterns of interaction would return. The fact that the Woodys, Jacksons and Dudleys were all able to sleep in front of me at times during the day for me indicates a degree of acceptance which goes beyond that of a short visit or interview.

Settling into the visit on day one is, in my view, a very important time. Just as if one has visitors to the house we would expect to have to entertain or amuse them, I was concerned to point out to the couples that they should carry out 'normal' activities. This was highlighted by my first ever visit to the Woodys on the pilot study. Patricia had arranged for me to come on a day which she knew would be busy and *'more exciting'* for me.

On arriving I found that a period of time would usually be spent updating each other on what had happened since the previous visit. This exchange of news was a vital part of getting to know the couples, and vice versa, and was helped by an extended stay. A shorter visit would leave little time for 'small talk' during a study, and yet it is this time that vital information can be uncovered. I also found that sitting down in the same room as the person with dementia and reading the newspaper or doing a puzzle helped to confirm to the carer that I was comfortable and that they could carry on their day in as 'normal' a way as possible.

Difficulties for the researcher

When you stay in someone else's home for three days you are really accepting to live under their conditions and according to their particular routines. I found this quite challenging. Firstly different food to get used to, for example many of the couple ate a lot of high fat puddings and used full fat milk. Three of the couples had decaffeinated tea and coffee, which on the first occasion caused me to have a withdrawal headache. I later began taking caffeine tablets with me as a precaution. The Dudley's forgot that I am a vegetarian, and so I ate meat on two occasions. These may sound like petty difficulties, but coupled with the strain of researching full time for three days, these little differences between my own and the couples' habits can add up. For the duration of my stay the only 'escape' would be at the end of the day after recording my notes in my sleeping bag. By then I was usually too tired to unwind by reading or listening to the radio as I would normally. Indeed recording the notes at the end of the day was a very important part of the data collection and had to be done despite tiredness. I found it very important to go through any notes I had made during the day, and any mapping I had done, and to regurgitate as much as possible onto tape from my mind before I could fully rest. Most times even after switching the tape off and turning out the light I had to turn it on again several times to add extra notes from my memory. The note reading and dictating would often take around 45 minutes to fully complete. My final thoughts spoken into the tape on my first ever night of a stay describe the agony of this;

Sunday: *'Oh I've actually got the light out now and I'm totally knackered, but you know the sort of knackered when you just can't go to sleep. And I'm kind of thinking oh god another very long day tomorrow followed by Tuesday, erm oh god can I actually stand this? Very very difficult to do. Is it easier to do short experiments? This is really in the field, this is trying to understand their lives. I'm going to try and go to sleep now.'*

Looking back, I found the first night of any visit the hardest, with the knowledge that there was another two days to go. With the second night I was comforted by the thought that this was my last night. However, an excerpt from my dictation on the second night of the above visit reveals that even the last night is still not in any way easy;

Monday: *'Hello. It's Monday and it's half past ten and I'm in bed and I'm totally and utterly knackered. I thought I was knackered yesterday. I didn't know the meaning of the word. Today I am DOG tired'.*

And later:

Monday: *'This has got to be one of the most knackering jobs I could ever think of doing. I can't think of any more at the moment......anyway, I'm going to go now cos I'm totally zonked but I'll probably remember something and come back later.'*

By the time Tuesday afternoon came, and I was leaving, I had one more tape to make as I drove back home;

Tuesday: *'Well it's quarter to four and I've just come back from the Jackson's and I am shattered. Erm I want to go somewhere now and just hide away from everybody, erm I don't want to see anybody, I don't want to talk to anybody, I just want to go and lie down, um but somewhere where nobody can find me. That sounds so weird but I am just so knackered from it all....'*

However, the tape ended on a positive note as I drove down to Milford on Sea to sit in the car park and stare out to sea, and the beautiful view of the Needles;

Tuesday: *'Nina (an organiser at the Alzheimer's Society lunch I had been to that day with the Jacksons) was saying that you have to be a certain kind of person to be interested in older people. I think she's right in some ways, and I love my work!'*

On leaving the couples after a stay I found I could best unwind by being totally alone for the evening and following day. This was easy when full time at Southampton University and, as above, I sometimes drove straight from the couples to the sea and walked along the coastline unwinding. However, latterly I moved back to London and began to teach part-time. This often meant that from a visit I would have to return straight to work, sometimes the same evening. This I found very difficult and would recommend that future researchers allow time for complete relaxation after any participant observation.

Effect of research on the couples

So that's the sort of effect doing the research had on me in the short term. But what about the couples? I have no doubt that it was difficult for them too although, as (Pointon 2000) points out, having someone outside of the family to talk to during a stay can be very therapeutic. Frances Archer described it as, *'I dump stuff on you!'*. Probably the most obvious effect was that of Jim Jackson deciding after my visit that he enjoyed talking to someone and that he would probably benefit from some time to himself, and hence he decided to arrange for Eileen to go to the day centre once a week.

Despite being hard work it was also very enjoyable to stay with the couples and I still visit Jim Jackson and the Woody's on occasion. I hope the couples also enjoyed my visits. One carer wrote that she felt they should be paying me after I had sent them a cheque! Some researchers see this 'bond' between researcher and researched as to be avoided, for example, (Wong 1998) states, *'As our rapport developed, I began the dangerous slide toward treating my respondents as friends'*. However, I feel that keeping the couples at a distance from me would have made the extended visits feel very 'unnatural'. It seemed easier, and preferable, to be myself with them and hopefully them with me.

Validity / reliability

Arguably one of the limitations of participant observation is the reliability of data collection. Although I made notes throughout the day where possible, for example when going to the toilet, or when writing in my puzzle book, most of the detailed notes were made by dictation at the end of the day. It could be argued that this may not be the most ideal method. However, I would suggest that this method enables the 'naturalness' of the visit to be paramount. The balance between data collection and retaining the normal flow of daily events is an interesting one. I would argue that the freedom offered by participant observation, and the interesting data it explores and reveals far outweighs the benefits of standardised data collection techniques. However, Dementia Care Mapping data was collected and this may help to bridge the gap between the two.

Overall I collected quantitative data (DCM and other measurements) and qualitative data (general observation / fieldnotes). An interesting possibility for helping to assess the reliability of the quantitative data would be to have two observers present, or for one to visit the same couple on a different occasion. Whilst I did discuss this possibility with another participant observer in the field of gerontology I decided that this would be asking too much of couples in the name of reliability.

As far as the qualitative data are concerned test-retest reliability is not an issue as it is expected that the observations will vary over time and place and that different researchers may come to different interpretations The key issue is to record these contextual aspects in such detail that a reader can take these into consideration when making a judgement about the work and that a clear audit trail is kept. Here the case study method becomes an ideal choice as it enables the researcher to check their interpretation of the situation by using different data collection techniques. For example, I was able to check well-being by using the mood scale of the Behaviour rating scale for Social and Psychological problems (van Loveren-Huyben, van der Bom, & Bronts 1988) as well as the indicators of well and ill-being, malignant social psychology , positive person work and Dementia Care Mapping.

Well-being and ill-being measures used

Within the case study approach a number of pre-existing measures of well/ill-being were used. This section looks at each in turn and considers their usefulness for assessing the well/ill-being of a person with dementia in a community setting. The use of Dementia Care Mapping within a community setting has not previously been carried out, and hence this ground breaking aspect of the study is explored.

Well-being and ill-being profiles

These were used to assess the person with dementia's well and ill-being at each visit. As well as giving a score of 0 for no signs, 1 for some signs and 2 for significant signs it was also decided to illustrate and corroborate these scores with written examples, presented in appendices five to nine. The scores enabled a trend over the longitudinal study to be observed, whereas the actual examples help to bring these scores to life. The scores were found to be consistent with the overall picture of the person's well-being as ascertained via the visits. The extended visit also allowed for all of the various aspects of the well/ill-being profiles to be explored. A shorter visit, perhaps during an interview, would not allow for this to be fully investigated and hence this method was felt to be useful for longer visits and to assess changes over time.

Dementia Care Mapping

From the outset it was recognised that Dementia Care Mapping was not originally intended for use in people's own homes. However the pilot study suggested that this might offer an additional way of presenting data, enabling the activities of the day to be recorded more fully.

Recording the data overtly was felt to be inappropriate at any stage of the visit and hence this would prove very difficult during Dementia Care Mapping. I found that I could store 30 minutes worth of coding in my mind at a time and then make notes, perhaps in the toilet. A more relaxed method was to use a puzzle book and make notes on the coding as the behaviour occurred. Clearly this is a distinction from Dementia Care Mapping used in formal care settings where the mapper is recording data overtly.

Mapping requires concentration and was found easiest within this research during 'quiet' periods of sitting or sleeping. It was also only possible when the observer was not interacting, as trying to map and talk at the same time proved difficult. This is also noted within mapping of formal care settings where the mapper may have to temporarily stop mapping to answer a resident's questions, for example. For mapping in a community setting it may be much easier with the researcher as complete observer rather than observer as participant. The data collected in this research may be necessarily biased in this way, and for this reason the data collected are presented in light of what happened throughout the day, i.e. outside of mapping times, as well (appendices five to nine). However even mapping during quiet times was found to have an advantage in the interpretation of events. For example in actually measuring the amount of time a person spent sleeping during the day I was alerted to the fact that Mr Woody had been sleeping for longer than the 'appropriate sleep' period of one and a half hours, hence it became possible to speculate that his excess sleeping could be caused by boredom or lack of stimulation. This again illustrates the advantage of the extended stay.

Mapping was found possible, for lengthy periods, with Gilbert Woody, Neil Dudley and Eileen Jackson, but impossible with Anne Reed and Monty Archer. What may strike the reader immediately is that the three couples where mapping was found possible were all in a positive state of well-being for most of the time. This may have meant that they were 'content' and easier to map. Anne Reed was in a high state of ill-being during my visit and because she sought my comfort on a number of occasions mapping became impossible and perhaps unethical in the sense that I felt providing comfort far exceeded the need for data collection. However the notes made where possible during the day and extensively at the end of the day illustrate her life effectively. With Monty Archer the main difficulty was that he spent a large amount of time talking to me and hence I felt that this was not at all what would be happening on a usual day. However, his stories were illuminating at a different level, for example in explaining his current behaviour.

For the three couples where mapping was possible it was illuminating to look for aspects of their life which could be further enhanced, for example

Neil Dudley's engagement with activities at the day centres was not matched at home, where his activities consisted of more passive things such as watching the television or listening to music. Claire Dudley herself recognised this, feeling that she wasn't able to provide the same mental stimulation for him at home. Similarly, Eileen Jackson was never observed to be agitated in the day centre and was engaged in various activities. However latterly at home she had become more agitated, perhaps looking for something to do. Hence in terms of an intervention Dementia Care Mapping could be used to help suggest additional activities which the person with dementia could undertake.

The ideal would be to map every person with dementia all of the time but the reality of the situation dictates otherwise. In summary Dementia Care Mapping is possible within a community setting and provides another useful way of looking at a person's activities and well-being

Politeness strategies

Found by Sabat (2001) to be useful in exploring intact abilities which could be missed by traditional batteries of tests, I watched out for and noted any politeness strategies used by the people with dementia in my study. Actions seemingly as simple as holding a door open for me (Monty Archer and Gilbert Woody) require a number of cognitive skills. Similarly Eileen Jackson recognising Jim Jackson's hearing loss and repeating herself. Hence to be mindful of politeness strategies whilst observing someone with dementia can add some extra information about their intact abilities. Again an extended observation is an ideal opportunity to look for these, as they may well be infrequent.

Aspects of selfhood

This theme, expanded by (Sabat et al. 1999) to look at the many facets of self, is an important one in dementia. Linked to personhood, considering aspects of self is useful in helping to build together a picture of the person

with dementia and their current situation. For example, Gilbert Woody's self as head of the family still remained intact with the vital help of his family, and I would argue, added to his overall positive well-being. On the other hand Monty Archer, excluded at times from his family, did not retain this aspect of self and hence faced erosion of his personhood. We can also compare Eileen Jackson and Anne Reed in looking at 'self as wife'. Clearly the difference between the two is amply illustrated by the case studies and, it could be argued, affected their well-being.
The aspects of self for this study were collected over time by observation, and show how a case study methodology can be very useful in looking at this important category.

Carer support for intact abilities

Sabat (2001) highlighted the importance of turning our attention away from the deficits of a person with dementia's abilities, as measured by traditional tests, to their remaining abilities. These intact abilities often require the help of another to be fully realised. During my visits a number of examples of this were observed. For example not feeding the person with dementia whilst they were still able to themselves, albeit by using a spoon. Mrs Dudley even noticed after a week's respite that her husband Neil was no longer trying to eat on his own, and so prompted him to re-use his existing skill which residential care staff had ignored. Similarly with dressing, many of the carers recognised that their relative could still complete certain tasks with their help, such as laying clothes out in the order in which they should be put on. Here observing these aspects of care help to illustrate how this part of personhood of the person with dementia can be retained as far as possible with the help of the carer.

Readers may recognise the overlap of some aspects of carer support for intact abilities with Kitwood and Bredin's (1992) facilitation category of positive person work. However it is felt to be a useful feature of care to note to help illuminate areas where personhood can be preserved, and in particular to note differences between home and other care settings as the above example illuminates.

Validation of emotion

As for carer support for intact abilities, this category was also noted under examples of positive person work as validation, necessitating some repetition. However it was felt to be important as it also helps to provide some indication of behaviour reflecting social death since validation of emotion would suggest that social death has not occurred. For example, throughout my visits Mrs Woody showed an acceptance and validation of Gilbert Woody's emotions, from his confusion on waking to his evident joy on seeing an old friend. Conversely the large number of examples of malignant social psychology observed during my visit to Mr and Mrs Reed are testament to the lack of validation Thomas showed Anne.

The Behaviour rating scale for Social and Psychological problems (BPS) and the Bristol Activities of Daily Living Scale (BADLS)

These scales were found useful in comparing the researcher's and carer's perceptions of the person with dementia's abilities and other aspects of their life such as mood. Similarly it enabled features of the case study to be corroborated, for example levels of well-being compared to the BPS mood scale. In addition any changes over time could be monitored.

The carer's perception of dementia

This was an important area in terms of methodology, since only (Sweeting & Gilhooly 1997) had attempted to measure this in the dementia care field. Incidences linked to social death beliefs or behaviour were noted as a matter of course during visits. Here malignant social psychology and positive person work were also indicators. These observations, combined with the interview transcripts were used to assess beliefs and behaviour of the carer with respect to social death of their relative. The interview on social death helped to illuminate this in a number of key ways; it asked the carer to consider whether their relative had changed since the onset of dementia, then to consider if their relationship had changed. Here some answers indicated belief in social death. For example Thomas Reed's view that they no longer had a relationship as he had become *'Anne's dog's body'*. Similarly this may help to understand why a carer may have a belief in social death, for example, Claire Dudley describing how Neil used to be very romantic and then suddenly forgot her birthday and showed no interest in their 40th wedding anniversary.

Questions about recognition also help to illuminate inconsistencies in belief with respect to social death. For example on asking Thomas Reed if Anne recognised other members of the family he replied, *'Funnily enough she did recognise some people'*, indicating that he would not have expected her to.

Tackling the area of communication between the couple helped to explore how the carer works with communication difficulties they may encounter. Claire Dudley relied on a good knowledge of Neil's previous habits and desires, using their unspoken teamwork developed during their years sailing together. Jim Jackson saw that a person with dementia lived *'in a void'* and felt that it was the duty of the carer to fill the void in some way, so as to help them.

The most revealing question was that asking about insight and lucid moments. Here it showed that all carers were surprised by lucid moments, with some seeing these as confirmation that there was 'someone in there'. This area may be a key topic for further investigation and as such is considered under suggestions for further work.

Furthering knowledge on psychosocial aspects of dementia

Dementia research in the community

The literature review demonstrated the lack of observational studies carried out in the person with dementia's own home, in particular studies evaluating the quality of life of people with dementia at home, despite the increasingly large number of people who do remain cared for in their own home. This in depth, longitudinal study of five couples lays down the challenge for other researchers to investigate this neglected area. Some may criticise the methodology and the small sample size, but the dialogue will have begun. This study lays bare the difficulties and frustrations, the joy and the tears, of day to day life with dementia but also recognises the hugely important work that carers do in keeping their relative with dementia socially alive, and hence retaining personhood.

Importance of psychosocial aspects

The case studies have provided a large number of much needed examples of both malignant social psychology and positive person work within a community setting. These examples, when read in the context of the person's life, can illustrate how important the interaction between the carer and the person with dementia is. Consider Anne Reed's difficult life with Thomas. As well as being in physical pain she is also subject to many examples of malignant social psychology. Compare her well-being with that of Eileen Jackson and we can see how the effects of positive interactions can have a different outcome. Similarly by comparing well-being and activities in both home and day centre care settings, it has enabled comparisons between them to be made. For example, Neil Dudley and Eileen Jackson's engagement in the day centre which was not matched by engagement in activities at home. By using case studies as the basis for exploration, it has been shown that a person's well-being can be assessed, and areas for potential work highlighted, just as would be done within a formal care setting.

As well as providing these useful examples, this study has looked at changes over time. This is very important as the course of dementia may be of many years duration. Studies carried out in the community are rare, rarer still longitudinal ones. Here the indicators of well and ill-being have been shown to help assess change over time. The value of longitudinal studies in this area has been amply demonstrated.

Sabat's (2001) work on the significance of interactions compliments that of Kitwood. In line with Sabat's use of case studies to help illuminate important psychosocial aspects of dementia this study also provides more case study examples of the nature of the disease in a social context. Further examples of abilities which would be missed by tests favoured by the medical world were shown. For example, in observing politeness strategies such as Messrs Woody and Archer saying, *'after you'* to me as we approached a door. Also important were examples of people with dementia recognising other people's plight, for example Mrs Jackson repeating herself for the benefit of her husband who suffered hearing loss. Similarly Mrs Jackson recognising the difficulties a fellow dementia sufferer was having in rolling a dice and showed her, with encouragement as she learned.

In addition examples of the importance of others in the maintenance of personhood in terms of (Sabat, Fath, Moghaddam, & Harré 1999) self three (requiring the help of others) have been provided. For example the Woody family maintain Gilbert Woody's status as head of the household by including him in mealtimes and social gathering as before. Whereas in contrast Monty Archer's family now exclude him at times and this leaves him feeling *'useless'*. This also shows how the quality and nature of pre-morbid relationships are important factors affecting well-being in dementia.

Finally examples of mislabelled behaviour, Sabat's (2001) *'cycle of misinterpretation'* when someone is positioned as ill, were observed. For example, Anne Reed's agitated behaviour in the day centre was seen as her *'being awkward'* until the staff became aware of her physical pain and began to validate her emotions. Here the importance of educating carers to look beyond the observed behaviour for rational reasons and motives has been highlighted.

Social death

This research addressed factors which may be at play in making carers treat their relative with dementia in ways which are damaging to their personhood. Carers viewing their relative as 'already dead', seeing them as socially dead, was highlighted as an area for investigation. The literature review, set out in chapter two, showed the work on social death to be sparse. (Sweeting & Gilhooly 1997), using an interview schedule and brief observation, noted the complex interaction between beliefs and behaviours relating to social death, noting inconsistencies. This study has added to the knowledge in this arena using a different method of eliciting carer's beliefs relating to social death and comparing them to observations made during the extended visits to draw up an overall picture. This served to further illustrate the complex interaction between beliefs and behaviours, corroborating Sweeting and Gilhooly's findings. The key part in terms of the maintenance of personhood for the person with dementia appears to be the carer's behaviour towards them 'as if' they were not socially dead. This study has shown that this behaviour is not always fuelled by beliefs. The relationship between behaviour and beliefs is complex and needs further attention.

Since behaving towards a person with dementia as if they were socially dead has implications for their well-being any possible area which could persuade the carer to act otherwise is important for research which may inform interventions or education for carers. Discussion of lucid moments with the carers in this study illustrated one possible area which may fuel belief that there may still be 'someone in there' in even the most sceptical of carer. A study looking at lucid moments and their effect on social death beliefs may help to illuminate this aspect further and is discussed below.

Future work

Introduction

This study has contributed to the much needed literature assessing well-being of people with dementia living in their own homes, demonstrating that it is both a feasible and fruitful area for research. But this is just the beginning. Many more studies are needed before areas for intervention or education of carers become truly apparent. In deciding priorities for research areas I present two topics which, I feel, particularly merit further attention and resources. These both relate to the findings made from my extended stays and both would ultimately help the well-being of the person with dementia. Firstly, as highlighted by Sabat (2001), if a person with dementia shows different levels of well-being in different settings it could be due to the effect of malignant social psychology. Clearly this provides a potential area for intervention. Secondly, as discussed in the previous section, lucid moments may prompt a carer to question their social death beliefs. These two important areas are discussed below.

Differences in behaviour between settings

This study has shown that there can be differences in behaviour of the person with dementia between different settings, for example home and day care centres. Observation of this difference could be used to work with the person with dementia and their carer to try and suggest where changes could be made to help with well-being. For example, Eileen Jackson had become quite agitated in her own home, looking for work and pacing between the kitchen and lounge. Jim would say, *'there's nothing you need to do'*. At the day centre Eileen was not observed to be agitated, and she would become engaged in activities such as weaving or mixing pastry. It may have been possible for Jim to try out some activities at home which would have settled Eileen from her pacing. Similarly Neil Dudley was seen to engage in a variety of activities at the day centre, but not at home. Indeed Claire Dudley felt she was not able to provide the kind of mental stimulation that he received from the day centre. However with help and support Claire, and other carers like her, could be helped to look at some of these possibilities. Many carers would be willing to try activities if shown how, and the benefits demonstrated to them.

However, in order to observe the person with dementia in different settings a long period of observation is most helpful. Hence any work with couples in this way would necessarily be expensive in terms of time, but this cost may be offset by considering the large cost of providing residential care for people with dementia when their relative feels they can no longer cope.

Lucid moments

All five of the carers expressed how they wondered what their relative 'knew'. Patricia Woody felt that Gilbert did understand what was going on at times, and didn't like to talk about his illness in front of him because of this. Despite some of Claire Archer's comments about Neil being a stranger and that looking after him was like *'looking after a cat'*, she was also surprised by some of his lucid moments, in particular one just before his death. Frances Archer found chatting to Monty *'pointless'* as he would often interrupt with an inappropriate question, however, she too was surprised by a lucid moment. Jim Jackson was fascinated by Eileen's lucidity, confirming his view that you should keep an *'open mind'* about what people with dementia understood of their situation, despite their inability to communicate this. Thomas Reed, whose examples of malignant social psychology in his interactions with Anne were indicative of his belief that she was socially dead, exclaimed surprise at her lucid moments. Could these glimpses of communication as understood by 'well/normal' people from the person with dementia hold an important key? It certainly may be one area where changing belief to behaviour could draw on. For example in asking a carer to give examples of lucid moments we may be able to help them to see 'the person' trapped inside by dementia. However, for some people it may be too frightening to entertain the possibility that someone with dementia may still be very much aware but unable to communicate this knowledge. Indeed (Normann, Asplund, & Norberg 1998) looked at how carers in formal settings narrated lucidity and found that the reactions were divided into joy and fear or confusion. So this is an important area but we must tread carefully. I would suggest a study looking at lucid moments experienced by carers of relatives with dementia living at home would be a good starting place.

Final remarks

For me the experience of carrying out this study has been a steep learning curve which, even as I write this, I feel I am still only part way up. When I began reading and enthusing about the work of Tom Kitwood I was brought back to earth by one of the criticisms of his work, namely that it is very idealistic. On paper and in theory it seems obvious that to treat someone with dementia as a person and to avoid malignant social psychology would be beneficial to the person with dementia's well-being. However, the reality of looking after someone 24 hours a day, seven days a week, can be very difficult. It is only since spending extended periods of time with the couples that I have been offered a glimpse of these difficulties. I may have been *'dog tired'* after my visits, but I could relax and unwind later. For carers this may be impossible. I found that the extended stays helped me to also view the situation from the carers' perspective. Kitwood (1995) himself warns against *'sanctifying or romanticising dementia; of treating it as a happy journey or a path of discovery'.* This study has certainly grounded me in that belief.

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