

Open Research Online

The Open University's repository of research publications and other research outputs

Being given a diagnosis of dementia: the experiences of people with dementia and people who care for someone with dementia

Thesis

How to cite:

Taylor, Rachel Jane (1996). Being given a diagnosis of dementia: the experiences of people with dementia and people who care for someone with dementia. PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 1996 The Author

Version: Version of Record

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

**Being given a diagnosis of dementia:
The experiences of people with dementia and
of people who care for someone with dementia**

JANE
RACHEL J. TAYLOR BA Hons.

Submitted in partial fulfilment of the requirements for the degree of
DOCTORATE OF CLINICAL PSYCHOLOGY

**CLINICAL PSYCHOLOGY
SALOMONS CENTRE
ACCREDITED INSTITUTION OF THE OPEN UNIVERSITY**

Date of award: 11th September 1996

SEPTEMBER 1996

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed *Rachel Taylor* (candidate)
Date *9 7 96*

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed *Rachel Taylor* (candidate)
Date *9 7 96*
Signed *P. J. VANANUS* (supervisor)
Date *9.7.96*

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed *Rachel Taylor* (candidate)
Date *9 7 96*

ACKNOWLEDGEMENTS

I would like to thank all the individuals who came forward to either to fill in the survey or take part in the interviews. I am grateful for their generosity in sharing their experiences with me. I would also like to thank all the services who were involved in the recruitment process. Their help was invaluable.¹

I would also like to thank Dr Jane Volans, Head of Psychology Services to Older Adults, Oxleas NHS Trust. Her knowledge of the subject area, support, and timely supervision have been invaluable. Thanks also to Dr Margie Callanan, Clinical Research Director, Dr Jan Burns, Assistant Director and Lynda Thompson, Research Assistant South Thames (Salomons) Clinical Psychology Training Scheme for their advice, support, practical help and encouragement.

Other people who have been very helpful during the course of the research include Michael Maltby, Head of Older Adults Clinical Psychology Service, Weald of Kent NHS Trust and Meg Rolleston, Clinical Psychologist, Oxleas NHS Trust, Laura Sutton, Clinical Psychologist, Jennifer Harbridge, South Thames (Salomons) Clinical Psychology Training Scheme, Ralph Voladon, Community Psychiatric Nurse, Tina Stirling, Carers First and the Bradford Dementia Research Group, Bradford University.

For Norman

¹The information contained in this document has been altered in order to preserve the anonymity of the people who took part.

BL form

TAYLOR, R



Library authorisation form
D.Clin.Psychol.

Please return this form to the Assistant Director (Registration and Conferments) Open University
Validation Services. 344-354 Gray's Inn Road. London WC1X 8BP.

Student: RACHEL JANE TAYLOR

Institution: SALOMONS CENTRE

Thesis title: BEING GIVEN A DIAGNOSIS OF DEMENTIA: THE
EXPERIENCES OF PEOPLE WITH DEMENTIA AND OF PEOPLE
WHO CARE FOR SOMEONE WITH DEMENTIA

Part 1 Open University Library Authorisation

I confirm that I am willing for my thesis to be made available to readers by the Open University
Library and for it to be photocopied, subject to the discretion of the Librarian.

Signed: R Taylor Date: 31/12/16

Part 2 British Library Authorisation

If you want a copy of your thesis to be available on loan to the British Library Thesis Service as and
when it is requested, you must sign a British Library Doctoral Thesis Agreement Form and return it to
OUVS together with this form. The British Library will publicize the details of your thesis and may
request a copy on loan from the University Library. Information on the presentation of the thesis is
given in the Agreement form.

The University has decided that your participation in the British Library Thesis Service should be
voluntary. Please tick one of the boxes below to indicate your intentions.

I am willing for the Open University to loan the British Library a copy of my thesis: a signed
British Library Doctoral Thesis Agreement Form is attached.

or

I do not wish the Open University to loan a copy of my thesis to the British Library.

Signed: R Taylor Date: 31/12/16

ABSTRACT:

This study explores the issues raised for people with dementia and their carers when they receive a diagnosis of dementia. Previous research suggests that more people with dementia than other serious illnesses such as cancer will not be told their diagnosis. The implications of this for the way that people with dementia adjust psychologically to their situation are reviewed. It is suggested that the complex illness concept and the particular nature of dementia as an illness influence communication about it

The research had three groups of participants. Twenty-six people caring for a relative with dementia completed a short survey. Two people with dementia and seven people caring for someone with dementia were interviewed face-to-face to gather in-depth information about their experiences of receiving and coping with a diagnosis. Grounded theory was used to analyse the interviews and a descriptive summary of the survey was produced. The survey confirmed that many people with dementia do not get told their diagnosis. The interviews described the issues raised for people with dementia, such as the feelings raised for them by having dementia and highlighted their ways of coping with dementia. The interviews with carers suggested that if sharing was an issue, the carers tried to strike a balance between remaining honest and protecting the person from the implications of the knowledge. Maintaining a sense of hope for the person seemed to be very important.

A critical discussion of the methodology is presented. The implications for future research and the clinical relevance of the research are also discussed.

CONTENTS

2.10	Summary of recruitment.....	37
	Acknowledgements.....	i
3	Results.....	37
3.1	Abstract.....	ii
3.2	Demographic details of survey participants.....	38
1.3	Introduction.....	1
1.1	The diagnosis of dementia.....	2
1.2	Psychological reactions to the diagnosis of terminal illness.....	4
1.3	Sharing information about a diagnosis of dementia.....	6
1.4	Research into the practice of medical professionals in degassing dementia.....	8
1.5	Research into the experience of carers and sharing information with the person they care for.....	10
1.6	The views of people without dementia about sharing information.....	13
1.7	The views of people with dementia about sharing information.....	14
1.8	Previous research on satisfaction with the diagnosis process.....	15
1.9	Summary: Previous research into the diagnosis process.....	16
1.10	Dementia as an illness concept.....	16
1.11	Psychodynamic and Psychosocial explanations of the way information is communicated about dementia: "Ignorance is bliss"?.	19
1.12	Summary.....	21
3.17	Openness.....	50
2.18	The current research study.....	22
2.19	The research questions.....	22
2.20	Quantitative and qualitative methodologies.....	23
2.3	The research population.....	26
2.4	Description of the survey.....	27
2.5	Development of the survey.....	29
2.6	Description of the interview schedules.....	30
2.7	Issues of reliability and validity in qualitative research.....	31

2.8	Ethical approval.....	34
2.9	Recruitment of participants.....	35
2.10	Summary of recruitment.....	37
3.	Results.....	37
3.1	Analysis of the survey.....	38
3.2	Demographic details of survey participants.....	38
3.3	Demographic details of the people with dementia being cared for by the survey participants.....	39
3.4	Time since diagnosis.....	39
3.5	Participants satisfaction with the information given about diagnosis...	40
3.6	Sharing information.....	41
3.6	Analysis of the interview transcripts.....	43
3.7	The interview participants: The people with dementia.....	43
3.8	Analysis of interviews with people with dementia.....	44
3.9	Problems identified to cope with.....	44
3.10	Ways of coping with dementia.....	44
3.11	Views about contact with health professionals.....	45
3.12	The interview participants: The carers.....	45
3.13	The process of receiving a diagnosis.....	46
3.14	Pre-diagnosis uncertainty.....	47
3.15	Sharing information.....	49
3.16	Cognitive impairment.....	49
3.17	Openness.....	50
3.18	Protectiveness.....	52
3.19	Contact with medical services.....	54
3.20	Helpful contact.....	55
3.21	Unhelpful contact.....	57
4.	Discussion.....	59
4.1	The design of the study.....	59
4.2	Recruitment strategies.....	60

4.3	Issues affecting the reliability and validity of the survey findings.....	61
4.4	The "trustworthiness" of the qualitative interviews.....	62
4.5	Discussion of results.....	64
4.6	Conclusions.....	70
4.7	Implications for further research.....	73
4.8	Implications for clinical work.....	74
	References.....	76
	Index of Appendices.....	80

List of Tables

1.	Recruitment sources.....	36
2.	Age of participants.....	38
3.	Relationship to person being cared for.....	38
4.	Demographic details of people being cared for by survey participants	39
5.	Satisfaction with information given about diagnosis.....	41
6.	Ratings by participants of the amount of information given to and understood by the person with dementia.....	42
7.	Who participants felt made the decision about how much information to share.....	42
8.	Level of agreement with statement about sharing.....	42
9.	Categories emerging from interviews with people with dementia.....	44
10.	Categories related to sharing information.....	49
11.	Categories related to contact with services.....	55
12.	Percentage agreement of second rater.....	63

List of figures:

1. Histogram showing distribution of time since carers had noticed cognitive changes in the person being cared for..... 40
2. Histogram showing distribution of time since a formal diagnosis had been received..... 40

The author notes that while the service manager said that having the words "Alzheimer's disease" in the name of the organisation could be a problem. She also said that in the presence of clients she might turn any focus away from the words Alzheimer's disease displayed too prominently. This was because she did not want to appear to cheer the client by letting them think they had Alzheimer's disease, even if they did. Her explanation was in part about the stigma associated with the words but also because many people using the service would not have been told that they had Alzheimer's disease or even dementia.

The intention of beginning with a "joke" is not to minimise the seriousness of dementia. Instead, the purpose of mentioning it and the personal, anecdotal experience in a day service is to illustrate the oneness which seems to exist around communicating information about dementia, particularly with the person themselves. The main aim of the current research was to explore some of the issues which were raised for people with dementia and for their families by a diagnosis of dementia. A secondary aim was to investigate how satisfied people with dementia and their families were at the time of diagnosis with their contact with health professionals.

The current research will be placed in context through a review of research literature relevant to the research questions. This includes research into psychological reactions to terminal illness, previous research into sharing a diagnosis of dementia from the point of view of health professionals, families, people without dementia and people who do have dementia and research into satisfaction with contact with health professionals in dementia care. Finally, two potential, theoretical explanations of

1. INTRODUCTION:

A man goes to visit his doctor:

Dr: I've got some bad news and some very bad news.

Man: Well, you had better give me the bad news first.

Dr I'm sorry to tell you but you have got Alzheimer's Disease.

Man: Oh no! What's the very bad news?

Dr I'm afraid that you have got terminal cancer.

Man: Oh well! That's all right then.

Dr: (Puzzled) Why is that all right?

Man: Well at least you didn't tell me I have got Alzheimer's disease.

On a visit to a voluntary organisation providing day care for people with dementia, the centre manager said that having the words "Alzheimer's Disease" in the name of the organisation could be a problem. She also said that in the presence of clients she might turn any books over that had the words Alzheimer's disease displayed too prominently. This was because she did not want to upset the client by letting them think they had Alzheimer's disease, even if they did. Her explanation was in part about the stigma associated with the words but also because many people using the service would not have been told that they had Alzheimer's disease or even dementia.

The intention of beginning with a "joke" is not to minimise the seriousness of dementia.

Instead, the purpose of recounting it and the personal, anecdotal experience in a day service is to illustrate the unease which seems to exist around communicating information about dementia, particularly with the person themselves. The main aim of the current research was to explore some of the issues which were raised for people with dementia and for their families by a diagnosis of dementia. A secondary aim was to investigate how satisfied people with dementia and their families were at the time of diagnosis with their contact with health professionals.

The current research will be placed in context through a review of research literature relevant to the research questions. This includes research into psychological reactions to terminal illness; previous research into sharing a diagnosis of dementia from the point of view of health professionals, families, people without dementia and people who do have dementia and research into satisfaction with contact with health professionals in dementia care. Finally, two potential, theoretical explanations of

factors which might influence the way information is shared in dementia will be reviewed.

1.1 The diagnosis of dementia:

The dementias of later life and Alzheimer's disease in particular are not disorders in their own right (Arendt & Jones 1992). They are complex syndromes of symptoms that show great variability and overlap with other, treatable dementias, depression and general ageing processes (Gubrium 1986; Iliffe 1995). The difficulty caused for diagnosis by this complexity is discussed in more detail later. However, they have been broadly categorised and some have been shown to have clear aetiologies.

The World Health Organisation provides the following definition of dementia:

"Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments in cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation." (p. 45, World Health Organisation 1992).

Approximately 500 000 people in the UK have dementia and the incidence and prevalence of dementia increase with age (Tobiansky 1994). Approximately five percent of people over sixty-five and twenty percent of people over eighty will have dementia. As the UK population ages and fewer people die from other causes, the absolute number of people with dementia will increase.

The most prevalent type of dementia is Alzheimer's disease which accounts for approximately fifty percent of all cases (Tobiansky 1994). Alzheimer's disease is characterised as having an insidious onset and a gradual progression. The aetiology of Alzheimer's disease is unclear and it may represent an artificial grouping of different disorders which have yet to be differentially identified (Arendt & Jones 1992). Multi-infarct dementia accounts for 10-15 percent of cases and results from cell death caused by small strokes. It occurs among older people with cardiovascular disease such as hypertension and has a clear aetiology and a step-wise deterioration as brain cells are damaged by discrete infarcts. In a further 10-15 percent of cases both Alzheimer's disease and multi-infarct dementia may be present and there are several much rarer forms such as diffuse Lewy body dementia, Parkinson related dementia and Pick's disease.

In order to aid clarity, the term "dementia" is used in this research to include all forms of dementia, including Alzheimer's Disease. It is acknowledged, however, that this could mask some important differences in experience. The deterioration in abilities experienced by people with dementia is such that a member of their social network and more usually family becomes responsible for many aspects of their care. Again, to aid clarity, "carer" will be used as a general term to describe such a person, although for people with only mild dementia, "carer" may not be a wholly accurate description of their relationship with this person.

1.2 Psychological reactions to the diagnosis of terminal illness:

Ilfie (1995) has argued that dementia is essentially a terminal illness for which approaches from palliative care are appropriate. There has been a little research into the subjective and emotional experience of dementia. In general, the areas of dementia care which have attracted most research are the biomedical aspects; the stress of caregiving and the modification of behaviours such as wandering or incontinence. Cotrell & Schulz (1993) conclude that "In the majority of research on Alzheimer's disease, the afflicted person is viewed as a disease entity to be studied rather than someone who can directly contribute to our understanding of the illness" (p.205). One of reasons for this lack of research may be that the information provided by people with dementia is seen as unreliable and invalid because of the inherent nature of cognitive impairment in dementia (Cotrell & Schulz 1993). However, this clearly underestimates the abilities of many people with dementia also ignores the usefulness of a qualitative approach for describing such experiences.

Keady Nolan & Gilliard (1994) provided a qualitative account of the issues faced by six people with dementia. They found that the people in their group had to deal with several issues including a growing sense of fear about future uncertainty; a the sense of being out of control; the effect of cumulative losses; feelings over anger about the dementia and a need to protect their families from these feelings. They also found that once the initial phase of fear had been overcome, their group tried to keep a positive frame of mind about the situation, summed up by them as "making the best of a bad job". This attitude was seen as crucial to adapting to the situation. Kitwood (1995)

has gone further and suggested that for some people, the experience of dementia results in a period of personal growth.

The work of Keady *et al.* (1995) reflects research into psychological reactions to other terminal illnesses. A number of reactions to a diagnosis of cancer have been recorded such as shock, guilt, anger, shame, fear and a feeling of overwhelming loss of control and uncertainty (Charlton 1992; Ford, Lewis & Fallowfield 1995; Harrison & McGuire 1994; Watson 1994). With a diagnosis of cancer, it is suggested that there is an initial period of intense shock that gives way to one of adjustment to the meaning of the diagnosis where the person comes to terms with the uncertainty, threat to life and possibility of an unpleasant treatment regime (Watson 1994). This process has been likened to a bereavement reaction where the person and their social network anticipate the loss and move through a similar process of grieving before death actually occurs (Harrison & McGuire 1994).

Epidemiological studies have found that between ten and forty-eight percent of people diagnosed with cancer show long-term psychological difficulties in reaching a period of adjustment to the illness (Watson 1994). Risk factors for such long-term psychological problems have been identified which include a previous history of depression and anxiety, few social supports and a pessimistic attitude to possible treatments. Furthermore, some coping styles have been found to be associated with better adjustment (Harrison & McGuire 1994). The most effective strategies appear to be those which are most proactive such as confronting the problem, seeking support and focusing on the positive. Strategies found to be associated with worse outcome

were denial of the seriousness, withdrawal from contact, tension reduction measures such as alcohol and drug use and blaming oneself and others. However, there is also some suggestion that in acute phases of diagnosis and treatment, the use of denial and distraction as coping strategies may be of more use in reducing anxiety (Harrison & McGuire 1994).

The importance of good communication between doctors and patients about life-threatening illnesses such as cancer has received a great deal of attention (Kendrick 1994). A key difference between dementia and other illnesses such as cancer is in the amount of information the person with dementia receives. Practice of delivering bad news about other illnesses has changed greatly in the last fifty years (Charlton 1992). A review of research relating to sharing bad news about cancer diagnoses shows a marked change towards more openness about sharing information (Charlton 1992). In the 1950s, it was common for doctors not to tell patients, but by the 1980s it was unusual if information was not shared. Charlton (1992) also reviewed the literature on patient preference which also showed an increasing trend of patients wanting more openness. The research presented below suggests that a much higher proportion of people with dementia are not given information about their diagnosis and prognosis which could have important implications for the coping strategies available for people with dementia.

1.3 Sharing Information about a diagnosis of dementia:

Having to give someone a diagnosis of any serious illness is difficult. An ethical dilemma is presented as both withholding and giving information have the potential to

harm the person. To withhold information, particularly about life-threatening conditions can be unethical. Kendrick (1994) cites Haring (1974) arguing this point:

"Loving care for the dying is one of the supreme expressions of our respect for the human person and of truthful relationships with him (sic) to deceive a dying person about the most crucial personal and awesome fact of his life, his approaching death, is to treat him like an object. It can mean robbing him of the most decisive act of freedom." (Kendrick 1994, p.5)

To let someone know risks precipitating an overwhelming loss of hope and depression, but it also allows the person the opportunity to make advance plans, settle affairs or to enable the psychological process of anticipated mourning of the loss (Erde, Nadall & Scholl 1988; Kendrick 1994; Faulkner, McGuire & Regnard 1994).

On the other hand, a utilitarian approach would see withholding information as being the "means to the end" of not causing further pain and distress. However, the medical ethics literature suggests that this approach can be harmful in the long term as it is often difficult to maintain an illusion that a seriously ill person is not going to die. This risks a betrayal of the ill person's trust in medical professionals and their loved ones at a time when it is most important (Faulkner, McGuire & Regnard 1994; Kendrick 1994). A practical, middle ground suggested to break bad news is to let the person themselves control the flow of information, for example by asking people what they would like to know before tests are carried out, by asking what they already suspect and what they understand by the terms used such as "cancer".

The same ethical dilemma is presented by having to give someone diagnosis of dementia (Husband 1996; Rice & Warner 1994; Erde Nadall & Scholl 1988).

However, the previous research suggests that because of the element of cognitive

impairment, information can often be given to the carer rather than the person directly, even when the person themselves might understand some of it. This then involves the carer in the dilemma of whether to share or not

Research on sharing a diagnosis of dementia has been carried out in four areas: The behaviour and views of doctors (Rice & Warner 1994; Wolff, Woods & Reid 1995); The experiences of carers (Bell 1995; Brodaty Griffin & Hadzi-Pavlovic 1990; Husband 1996; Rice & Warner 1995); People without dementia (Erde *et al.* 1988) and some limited work with people who have dementia (Wolff *et al.* 1995).

1.4 Research into the practice of medical professionals in diagnosing dementia:

There has been a limited amount of research into the practice of health professionals sharing information when they diagnose dementia. For example, Rice & Warner (1994) asked around 250 doctors working with older adults to indicate the frequency of giving information on both diagnosis and prognosis to people with dementia and their carers. The survey asked them to make a distinction between people with mild, moderate and severe dementia. The participants were asked to estimate the percentage in each group that they would give full information to. Over 80 percent of the doctors surveyed said that they rarely told a person with severe dementia. However, in the cases of mild or moderate dementia the practice was much more mixed, indicating a much wider variation in practice. In addition, there were doctors who consistently told and doctors who consistently withheld information. However, whilst it was variable whether a person with dementia would be told, almost 100 percent of the doctors surveyed said that they told carers. This suggests that there are frequently times when

a carer may know of a diagnosis and prognosis whilst the person with dementia does not.

Rice & Warner (1994) also recorded qualitative comments given by participants about the reasons for sharing or not sharing. These were not to disclose because of the potential stress and harm to the person; to take cues from the person about how much information to give and to be "economical with the truth" by using terms such as "brain shrinkage", "old age" or "memory loss" instead of dementia. Also included in the last category were instances when a diagnosis was given but without a prognosis. Rice & Warner (1995) conclude that "telling a diagnosis without a prognosis in mild dementia could be seen as similar to using euphemisms" (p.470).

Although the findings of this study are interesting, there are a number of methodological problems which make the results tentative. Terms used in the research were not well defined. For example the authors acknowledge that "mild", "moderate" and "severe" dementia and "telling" were not precisely defined leading to potentially unreliable results. Secondly, the authors also acknowledge that the participants were asked to judge their practice retrospectively without reference to case reports which could lead to inaccuracy and bias. The possibility of a response bias in favour of reporting what might be seen as "good" practice rather than actual practice is not acknowledged. A prospective study which collected information perhaps by taping actual consultations would produce more comprehensive information.

In a similar study Wolff *et al.* (1995) asked a sample of thirty-five Scottish old age psychiatrists and a representative sample of thirty-five Glasgow general practitioners whether a person with early dementia should know their diagnosis. One third of the GPs and one fifth of psychiatrists were unsure whether the person should know. They reported that a small majority of consultants would inform the person. They conclude that:

"Not surprisingly, there remains doubt about telling the mildly demented patient the diagnosis among both psychiatrists and general practitioners. If there is an expectation of relentless deterioration to a state of incoherence and incontinence, and a "second infancy", the doctor may prefer to delay the bad news for as long as possible" (p.67).

The results complement those of the Rice & Warner (1994) study but are also subject to the same methodological problem of reporting practice retrospectively.

1.5 Research into the experiences of carers and sharing information with the person they care for:

Brodaty *et al.* (1990) found that for their sample of 188 carers who had contact with the Alzheimer's and Related Disorders Society (ADARDS), (the Australian equivalent of the UK Alzheimer's Disease Society), thirty-nine percent of the people they cared for had not been told the diagnosis. Twenty-three percent of those who had been told had been told by a GP, 13 percent by another health professional and 26 percent by a relative. Seventy-five percent of people with dementia had not been given information about prognosis and sixty-nine percent of the carers said that they had difficulty talking to the person they cared for about dementia. They also found that the people with dementia were not generally included in the process. Only two percent of carers

thought that the person should be told the diagnosis first and alone and forty-eight percent of the participants who had been told the diagnosis with the person would have preferred to hear it alone.

Whilst the results of the study are interesting, they are limited by the retrospective nature of the accounts and the method of sampling. Retrospective recall of information about diagnosis may be unreliable. Important information may be forgotten or confused and processes such as denial and selective remembering could distort recall. All the carers were recruited through ADARDS, a self-help group. The sample may therefore be biased towards those people who might already be dissatisfied with professional care. Brodaty *et al.* (1990) acknowledge this, but also suggest that those people with the resources to join ADARDS may also have had more resources to deal with professionals in the first place. The findings are therefore only generalisable to similar groups of carers actively involved in such groups. However, there may be additional difficulties in generalising the findings of this study to a UK population. For instance, the percentage of older people with moderate or severe dementia living in nursing homes is twice that in the UK (Brodaty *et al.* 1990). This may reflect important cultural differences towards the care of people with dementia. Brodaty *et al.* (1990) conclude that "In breaking the news of dementia, it appears preferable to first tell the carer alone and then to tell the patient and carer together. By openly discussing diagnosis, prognosis and management, health professionals can help ease the burden of the families of dementia sufferers" (p.376). Their conclusion provides one definition of good practice, but unfortunately it is not one which takes into account the diversity of views expressed by their participants, some of whom did

wish to be told first together. They also assume that all people with dementia want to know that they have dementia and would be able to cope with this knowledge.

Husband (1996) researched carers experiences of sharing information. She asked 42 family carers about sharing the diagnosis. She found that 21.4 per cent had shared the diagnosis, all of whom had no regrets about this. Sixty-seven per cent of those who had not told were clear that this was the right thing to do, leaving 33 per cent who were not sure. Only 4.7 per cent received any advice from a professional about sharing and 69 per cent felt that this would have been useful. She also asked carers why they had chosen to share or not share. The three most common reasons given for sharing were that the person already suspected dementia, wanting to treat the person as an adult and needing to maintain an open and honest relationship with the person. The five most common reasons for not sharing the diagnosis were that it would be too disturbing and the person needed to be protected; that they would be unable to understand it; that nothing could be done so nothing could be gained by telling; that the person feared being "put away" and finally, that they had long-standing fears of developing dementia.

A similar, unpublished study reported by Rice & Warner (1995) surveyed forty carers of people with established dementia. Of these carers, ninety per cent felt that there was never a right time for the person to be told the diagnosis. Unfortunately, not enough information is available about the study to make much use of the findings. It is not clear what questions were asked. If they were asked whether or not there was a "right time" to tell, it is perhaps not surprising that more participants felt this not to be

the case than in response to a more neutrally worded question in the survey conducted by Husband (1996).

Finally, Bell (1995), a family carer, wrote the following, personal account entitled "To tell or not to tell?"

The question haunted me from the moment my mother's Alzheimer's disease was diagnosed. I reasoned that to tell my mother the truth of her condition would somehow be an act of disloyalty. Deep down I wasn't sure if she could handle it and I was unwilling to jeopardise what had always been a relationship which I cherished. However, I came to realise that I was shouldering all the responsibility for what Alzheimer's was doing to both of us. By keeping the truth from her I was also denying her right to that truth even if she couldn't perhaps understand its full meaning. I knew I would recognise the right moment to share the load. I just had to hope that it would all come out in a calm and reasoned manner. It did. My mother sat quietly and listened, asked a few pertinent questions, and shed some tears. "Well," she said finally, we'll just have to do the best we can, won't we?" Since then, "Alzheimer's disease" has come into frequent usage in our household when it seems appropriate as an explanation. It seems to work better than citing bad memory or forgetfulness as a reason for my mother not being able to do certain things. She seems able to draw both relief and some understanding from those two words. The shared load is lighter than the burden I carried alone. My own anguish has lessened and while I dread what lies ahead, I know I was right to tell her the truth." (p. 4)

1.6 The views of people without dementia about sharing information:

Erde *et al.* (1988) investigated the specific question of whether or not a person in the early stages of dementia, who still had enough insight to understand the diagnosis should be told. They investigated this by inferring the views of people with dementia from the views of people without. They did this by showing a sample of 224 American adults without dementia a case vignette of a person with Alzheimer's disease. They then asked them whether or not they would like to be told the diagnosis if they were the person in the vignette. Of the sample, 91.9 percent said that they would like to be

told. The reasons they gave were to plan for the future (94 percent); to get a second opinion (62 percent); to settle affairs (36 percent) and to travel (15 percent).

These figures suggest that a large majority of people would like to be told. However, there are a number of methodological problems which mean the research should be treated with caution when applying it to people who actually have Alzheimer's disease. The people asked were not actually in the position of having dementia (Brody & Tomlinson 1988) and the vignette given described a worse-case scenario, both of which may have influenced the responses given by the participants. As with Brodaty *et al.* (1990) the generalisability of the results to a UK population may not be possible because of unknown cultural differences in attitudes towards dementia.

1.7 The views of people with dementia about sharing information:

Wolff *et al.* (1995) report an unpublished study of self-referrals to a Glasgow memory clinic where the majority of people wished to know their diagnosis. The study has advantages over Erde *et al.* (1988) as it is a finding from a sample of people with memory impairment. However, people who self-refer to a memory clinic might represent a group of people with very different views on sharing diagnosis and the finding may not be generalisable to a wider population of people with dementia.

1.8 Previous research on satisfaction with the diagnosis process:

In addition to the issue of sharing information, the second aim of the research was to explore communication about dementia at a broader level by investigating how satisfied people with dementia and carers were with the diagnosis process. Previous

research into the experiences of carers in this area will be reviewed. No previous research into the experiences of people with dementia specifically of satisfaction with the diagnosis process has been carried out.

Studies by Iliffe, Booroff, Gallivan, Morgan & Haines (1990) and Iliffe (1995a) found that carers were critical of general practitioners for being reluctant to make an initial diagnosis of dementia and failing to refer people to secondary services early enough. Furthermore, he found that even when general practitioners were trained to use an assessment tool (The Mini-Mental State Examination (MMSE) which increased the number of people identified with potential dementia, their referral behaviour still did not change. Iliffe (1994) and Woods (1995) suggest that this lack of referral comes from an overly pessimistic attitude which they term "therapeutic nihilism".

The study carried out by Brodaty *et al.* (1990) also asked about satisfaction. Eighty-four percent of their sample had been told the diagnosis by a health professional. Of these, only two thirds remembered being told something about prognosis. The study also examined the satisfaction of carers with the way information was given. Forty-eight percent said they had been told the diagnosis by the person they felt should have told them. Sixty-five percent of the carers were told the diagnosis alone and 21 percent were told with the person with dementia. Fifty-six percent wanted to be told alone and 31 percent wanted the diagnosis to be given with the person there. When actual and preferred experiences were compared, the diagnosis was first given by the preferred professional about half the time and to the preferred recipient about two-thirds of the time. Brodaty *et al.* (1990) concluded that carers often receive

inadequate information. They found that most initial diagnoses were vague and that fewer than half their sample were given information about management or prognosis.

1.9 Summary: Previous research into the sharing process:

The research presented shows that the practice of health professionals and the attitudes of carers can be varied when it comes to communicating information about a diagnosis with the person themselves and that some carers are dissatisfied with the information they receive and the way they are given it. Two potential explanations for the problems of communicating about dementia will now be discussed. The first is that the illness concept of dementia is so complex that a diagnosis cannot be made until cognitive impairment is so severe it precludes sharing this information. The second is that the seriousness and particular impact of dementia as an illness influences the way in which information is communicated through unconscious interpersonal and social processes.

1.10 Dementia as an illness concept:

The diagnosis of dementia can often be uncertain and inaccurate. In practice, dementia is diagnosed on the basis of information about clinical presentation and the results of further investigations such as computed tomography (CT) scans and neuropsychological assessment. Alzheimer's disease in particular is usually diagnosed by a process of systematic exclusion of other, treatable possibilities (Jutagir 1994; Tobiansky 1994). At post-mortem examination, diagnosis can be made more certainly. It also has elements which overlap with other conditions such as depression and the

cut-off between "normal" changes with age and dementia is not firmly set (Jutagir 1994).

Some neuropathological research has indicated that the current state of knowledge about brain neuropathology is insufficient to explain all post-mortem findings. Two studies comparing diagnosis whilst alive and diagnosis based on post-mortem examination found considerable inaccuracy. Molsa (1984) found that 85-90 percent of diagnoses were correct whilst Homer, Honavar, Lantos, Hastie, Kellett & Millard (1988) found that 11 out of 27 diagnoses of dementia were incorrect. The neuropathological features thought to be characteristic of Alzheimer's disease such as neurofibrillary tangles, excessive amyloid protein and senile plaques have been identified in the brains of people with no clinical symptoms of dementia (Homer *et al.* 1988; Kitwood 1988). Accurate and reliable information about the prognosis of dementia is also difficult to give. Clinical observation suggest there is much variability in the course of dementia. In more systematic research studies, methodological differences in the inclusion criteria make them difficult to compare (Tobiansky 1994). Some studies (for example Rossor 1993) have found a median survival time for Alzheimer's disease of seven to ten years from onset. However, given the difficulties inherent in pinpointing onset and giving a diagnosis, the length of time from onset to death is probably not particularly reliable.

Gubrium (1986, 1987) examined the construction of dementia as an illness concept. His conclusions are derived from analysis of qualitative interviews, documentary evidence and observations of people involved with dementia care. He suggested that the working models that these people hold are complex. In part this is because of the

first is the overlap of dementia with "normal ageing" which makes it difficult to differentiate. Secondly, it is because people hold two different descriptions of the dementia simultaneously. He describes these as a "chaotic" model and a "stage-like" model and observed that these two views could be held together by the same person without necessarily being dissonant. He concluded that these two different perspectives on dementia are descriptions serving different needs. When it is necessary to understand the disorder in a way which makes action possible, then the stage-like order is stressed. When it is necessary to talk about the difficulties or "tribulations" of living with the illness, then the diversity is stressed. Furthermore, the side of the illness which is emphasised depends on the perspective and needs of the person and the purpose of the communication about the disease.

There are obviously difficulties in organising the diverse experiences of dementia into a coherent illness concept which can be used to communicate clear information about diagnosis and prognosis. This could be a partial explanation for the low levels of satisfaction of carers of their contact with health professionals. Additionally, as a diagnosis might not be given (or even looked for) until cognitive impairment has progressed to a certain level, sharing information could be impossible because the person would not understand the already complex picture. However, Rice & Warner (1994) that the diagnosis was still shared only with the carer even when the person was rated as having only mild dementia, suggesting that there are other issues which influence sharing.

1.11 Psychodynamic and psychosocial explanations of the way information is communicated about dementia: "Ignorance is bliss?"

What remains open to speculation is the extent to which communication about and the process of adaptation to, the losses involved in dementia is influenced by the nature of the condition. Dementia involves many losses. These can be of skills and abilities once possessed, of independence and of social support networks. However, dementia has been described as a "living death" (Woods 1995) because of the potential for a profound loss self as cognitive function and memory deteriorate, as the following description illustrates:

You have to begin to lose your memory, if only in bits and pieces to realise that memory is what makes our lives. Life without memory is no life at all. Our memory is our coherence, our reasons, our feeling, even our action. Without it we are nothing" Luis Bunuel quoted by Killick 1994, p.6)

It has been suggested that this influences and disrupts communication about the illness (De Lepelierre *et al.* 1994; Sinason 1992). Sinason (1992) presents a psychodynamic account of the way in which people with cognitive impairment are treated. This account is also echoed by the psycho-social theory of Kitwood (1990, 1993). Sinason (1992) points out that the original meaning of the word "stupid" as "numbed by grief" and suggests that whilst some impairment of cognitive ability is organic, some is also the result of the intense psychological pain felt by the person about their losses. She also extends this to the need of people without dementia to defend themselves against such a painful emotional experience and personal fears of stupidity and mortality. As a result, the emotional needs of people with cognitive impairment are not acknowledged. She concludes that some people:

"Have subscribed to the hopeful myth that "ignorance is bliss". Ignorance is not bliss and neither is knowledge. In facing the tragedy of incapacity there is no easy stance. Where a condition is incurable and the progression is one of unremitting mental deterioration it is not surprising that the wish for ignorance should be strong" (Sinason 1992, p.87)

Kitwood (1993) has described a psychosocial model of dementia which has some similarities with Sinason's psychodynamic model. He suggests that the neurological impairment present in dementia is worsened by the action of what he terms "malignant social processes". These create a downward spiral of deterioration, above and beyond what would be created by the underlying neurological impairment. He identifies ten separate such processes, although some seem to overlap and be closely linked to one another. They include coercion of the person through use of deception; disempowerment; infantilisation; intimidation; labelling the person in such a way that a self-fulfilling prophecy is created; stigmatisation; outpacing the person's level of understanding; invalidation of the person's subjective experiences; banishment by removal of the person from contact with other people either physically or psychologically and objectification where the person is treated as if they were an object rather than a person.

Kitwood (1993) suggests four reasons why these malignant social processes occur. Firstly, that training for carers and life in general does not dispose people to be insightful and empathic. Secondly, services and family carers often lack resources and are overburdened and exhausted. Thirdly, because of the stereotypical, nihilistic view of dementia that nothing can be done and that people with dementia are "dead already". Finally, Kitwood also suggests that the malignant social processes occur

because there may be an unconscious effort to defend against the fear of mortality and loss of self present in dementia.

Some of the processes identified by Kitwood could be directly relevant to the sharing of information with the person about diagnosis and prognosis. For example, disempowerment by not giving information; treating the person as if they were a child; outpacing the person by giving information which is too complex; invalidation by ignoring the person's feelings and objectification by treating the person as if they were already dead. Labelling and stigmatisation raise different issues. Whilst giving information may reduce anxiety, at present, attitudes towards dementia are sometimes so negative that a self-fulfilling prophecy of deterioration could be created. This creates additional complexity to the issue how people with dementia react and cope with information about their condition.

1.12 Summary:

Communication about dementia is a complex area. The psychological implications of a receiving a diagnosis of dementia are not well understood. The research reviewed suggests that people with dementia are sometimes unlikely to be told their diagnosis and prognosis, but the effect of this on their adjustment to the situation are also unknown. As a result, carers become involved in the process of sharing information. Other research also suggests that in general levels of satisfaction with communication by health professionals about dementia among carers are not high and that in general, the views of people with dementia themselves are not widely researched. Ultimately, the only way in which we can begin to understand what would be desirable practice in

the area of giving and sharing information about dementia is try to listen more directly to the experiences of people with dementia and those closest to them have to say about their experiences.

2. THE CURRENT RESEARCH STUDY:

2.1 The research questions:

Previous research on the diagnosis process in dementia has been limited to the practice and views of health professionals and carers. As no previous research has taken place into the views and experiences of people with dementia when they receive a diagnosis, the first aim of the current research was to explore this area. The second aim was to extend the existing research into the experiences of carers of the diagnosis process and the issues raised by sharing information.

In the light of this lack of previous research and some practical considerations which will be discussed below, a decision was made to use both qualitative and quantitative methods. In order to provide some preliminary information about the experiences of people in the early stages of dementia, the following questions were explored using qualitative interviews:

- (1) What are the experiences of a small group of people with dementia of the diagnosis process?
- (2) How satisfied were this group with the way in which they were given information about the dementia?

The next questions were posed to extend the research on carers' experiences using a quantitative survey:

- (3) What proportion of carers were satisfied with the amount of information they received at the time their relative was diagnosed with dementia?
- (4) What proportion of carers were satisfied that the information they received was easy enough to understand?
- (5) What proportion of carers were satisfied with the way in which they were given the information?
- (6) What proportion of carers shared information they were given about dementia with person they care for?
- (7) How much information do carers feel a person with dementia should be given?

The aim of the quantitative survey was to provide broad information about the experiences of a larger group of carers. In order to provide a more detailed account of the experiences of some of these carers, the following questions were explored using qualitative interviews:

- (8) If sharing information with the person was an issue, what are the factors identified by the group which influenced their decision to share or not share information about diagnosis with the person they care for?
- (9) What are the factors identified by the group of carers as helpful and unhelpful in their contact with services at the time their relative received a diagnosis of dementia?

2.2 Quantitative and Qualitative Methodologies:

Qualitative approaches are commonly used in disciplines such as social anthropology and sociology, but their use in applied psychology is less widespread where traditional quantitative methods prevail. In view of this, the rationale for using both quantitative

and qualitative methods in the current study and the main differences between the two will be reviewed.

There are differences between quantitative and qualitative methods on both practical and a philosophical level. However, in some circumstances it is appropriate for them to be used together (Mason 1994). Qualitative research methods are more suited to particular research areas, for example, those where complex meanings of experience are being investigated, or where existing theory seems exhausted and where little information about an area is available (Bryman & Burgess 1994; Elliott 1994; Henwood & Pidgeon 1995; Jones 1995).

Qualitative methods were used in the present study for the following reasons; the scarcity of previous research made it an appropriate approach to describe the experiences of people with dementia; the nature of cognitive impairment in dementia suggested that face-to-face interviews were an appropriate way of gathering such information; the research questions tackled a sensitive area and the impact of the research could be more effectively monitored in an interview (Gubrium 1992; Gubrium & Sankar 1994).

At a practical level, qualitative research involves the collection of non-numerical data from interviews, documentary sources and observation which is analysed using non-mathematical procedures. Many forms and variations of qualitative data analysis have been developed and all provide in-depth information about the area under study (Patton 1987). At a philosophical level, quantitative and qualitative research methods

have a very different stance towards the meaning of "truth". Philosophically, the quantitative or positivist research paradigm regards knowledge as an objective truth "out there" to be discovered and which can be described by abstract and universal laws. This paradigm is prevalent in much traditional psychological research where pre-formed hypotheses are tested through manipulation and measurement of different, pre-defined variables. In contrast, the assumptions underlying qualitative research are that there are many ways of understanding the world; that knowledge is contextualised and local; that theory is built from the data rather than tested through the data collection and the researcher is not regarded as objective and uninvolved, but to directly influence the construction of the account presented.

The method chosen to analyse the qualitative data in the present study was the "framework" approach described by Ritchie & Spencer (1994). This is based on grounded theory, a particular approach to qualitative research (Strauss & Corbin 1990). Grounded theory, generates a theory or account inductively from data which is analysed in several stages to produce an account of the area being studied. The end point is an abstract theory which accounts for the experiences of the participants.

In grounded theory data collection and analysis are not separate stages, but occur simultaneously. As categories or a theme emerges from the original data, further data is collected to extend the theory. Sampling of new situations or participants is driven by the emerging theory, a process known as "theoretical sampling", and could be repeated several times in the generation of a theory. Depending on the nature of the research questions and the area under study, not all stages of grounded theory will be

applicable in every research study (Bryman & Burgess 1994). A limitation of the use of grounded theory in the present study is that it was not possible to extend beyond one round of data collection.

2.3 The research population:

Two groups of participants were included in the study. The group of people with dementia had to be aged over 60 years and to have only mild cognitive impairment. Younger people were not included because of the tentative suggestion from Husband (1996) that those under sixty received more information. For obvious ethical reasons they had to have been told their diagnosis, to have remembered such information and want to participate in a research interview. It was anticipated that these criteria would cause problems for recruitment because of the complex and difficult nature of dementia diagnosis. In the early stages, dementia is not an easy condition to diagnose with any certainty, a formal diagnosis might not be made (or looked for) until the memory difficulties and other cognitive impairments have progressed to a certain level of seriousness. At the point at which a diagnosis is fairly certain, the more likely that the level of cognitive impairment would preclude the person from participating in the research interview. However, despite the anticipated difficulties it was felt important to pursue this part of the study.

The inclusion criteria for carers were that they should be caring at home for a person over the age of 60. This person should have been given a diagnosis of dementia within the last year as the length of time since diagnosis may have had an independent influence on levels of satisfaction. A previous study of carers (Brodaty et al 1990)

recruited only carers who were in contact with a voluntary organisation. In order to recruit a wider sample of carers a wider range of statutory and voluntary services were approached for recruitment.

2.4 Description of the survey:

The aim of the survey was to collect information from carers about the experience of receiving information from professionals and about sharing information with the person they care for. The survey was divided into sections covering demographic information, finding out about dementia, sharing information and an evaluation of the questionnaire. A copy of the information sheet and questionnaire can be found in appendices one and two.

Sections A and B:

These sections asked for relationship between carer and cared for, age, gender and ethnic origin of both. In addition, carers were asked to estimate the amount of care that the person needed and whether they also had other health problems. These questions provided basic information about the survey sample.

Gaining a reliable measure of level of severity of a complex condition such as dementia is difficult. Some previous research such as Rice & Warner (1994) can be criticised for using ambiguous terms such as "mild", "moderate" and "severe". Questions B4 and B5 contained more detailed descriptions which included impact on everyday life and among of care need to provide a more reliable measure. However, it is acknowledged that these are still open to interpretation.

Section C:

This section asked about the information given by professionals. Participants were asked to estimate approximately how long since they had begun to notice the dementia and to estimate how long since they received a formal diagnosis. Participants were then asked what diagnosis had been given.

They were then asked about satisfaction with the amount of the information, how easy it was to understand and their overall satisfaction with the way in which they were told. They were asked to rate these on four point scales from "very happy" to "very unhappy" or "very easy" to "very difficult". The next three questions dealt with sharing information with the person they cared for. They were asked how much information the person had received, who had decided how much information to give them and how well carers felt the person understood any information they had been given. These questions are subject to the same problems of unreliability because of their retrospective nature.

Section D:

This contained only one question asking participants to rate how strongly they agreed with the statement "A person with dementia should be given all the information about their diagnosis". A four point scale ranging from strongly disagree to strongly agree was provided. This question was included to see what overall opinions were held by the participants. This was felt to be important in view of the position taken in some of the literature about breaking bad news that people have an absolute right to information about a diagnosis and by the Brodaty *et al.* (1990) study. Research in

dementia has suggested that if such a position is taken by professionals, it could place them in considerable conflict with carers. Half a page was then left blank and an invitation given to use it to record any other comments and to write about anything not covered by the survey.

Section E:

Provided participants with an opportunity to evaluate the survey. They were asked to rate how easy it was to fill in and how happy they were with the way they had been approached to fill it in. If they were unhappy with this, a space was provided for them to say why.

The survey was presented in large, clear text and an attempt was made to use clear language so that it was accessible to as many people as possible. The majority of questions were answered by ticking an appropriate box. For other questions such as asking for time since diagnosis and nature of physical health problems, space was left for participants to fill in what was appropriate to them.

2.5 Development of the survey:

A draft copy was shown to clinical psychologists and voluntary sector workers who were working with older adults with dementia. Comments made about the questions, language and lay-out of the survey were incorporated into a final draft. Two suggestions were made which were not acted on. These were to include a question about carers' health and a question carers' mental health, particularly difficulties with

depression. Both were potentially interesting areas with a bearing on how satisfied carers might be with information and how they might feel about sharing it. However, it was important to keep the questionnaire reasonably short to maximise participation. A question about depression in particular would have been quite complex to achieve enough information to provide a valid response. The first five questionnaires returned were reviewed as a pilot. Only one minor change was made to question C7 to allow an option for those people who had received no information at all.

2.6 Description of the interview schedules:

Two interview schedules were developed for the semi-structured interviews. Each participant was read a standard introduction to the research interview. The first interview in each group was used as a pilot, but no changes were made. Information sheets and schedules can be found in appendices 3-6.

The interview for people with dementia contained two sections:

(1) Questions about what information was given: Age; length of time since diagnosis; what information was given about diagnosis and prognosis; how information was given.

(2) Questions about satisfaction with the information: Satisfaction with information; satisfaction with the way it was delivered; most and least helpful aspects of the process.

The interview for people caring for someone with dementia contained three sections:

(1) Background information and questions about what information was given:

Age and relationship to person with dementia; length of time since finding out about diagnosis; how this information was given; what information was given about diagnosis and prognosis; amount of prior information about dementia.

(2) Questions about satisfaction with the information: Helpfulness of information; satisfaction with the way you were told; most and least helpful aspect of process.

(3) Questions about sharing the information with the person they care for:

Whether relative knows what is wrong with them; whether they were told at the same time; how well they feel person understood the information; who decided how much to tell them; what was taken into account in the decision to share or not share; if their relative was told, satisfaction with the way in which this was done.

2.7 Issues of reliability and validity and qualitative research:

Reliability and validity of research data and analysis are concepts which have been developed within the quantitative paradigm to evaluate the quality of research. As such, they are concepts which are difficult to apply to qualitative research where there is no objective truth to be valid and reliable. However, some criteria have to be used to evaluate the quality of qualitative research. Whilst some qualitative researchers

maintain that any attempt to apply validity and reliability pre-supposes that we can know "truth", others have produced concepts to assess qualitative research which are much more akin to concepts of reliability and validity in quantitative research. Some middle ground is found in the concept of "trustworthiness" which attempts to re-label traditional terms in a way that is meaningful to qualitative research (Miles & Huberman 1994). "Trustworthiness" consists of four components credibility or internal validity; transferability or external validity; dependability or reliability and confirmability or objectivity. In addition, a fifth category of "utility" is also used. These criteria have been used during the design and implementation of the present study.

Credibility or internal validity:

The nature of qualitative research is to provide a credible account of the meaning of an experience or phenomena. The account should have what has been termed "rhetorical power" (Henwood & Pidgeon 1995). It should persuade the reader that it is the account which fits the data best. One important audience are the participants themselves and credibility can be checked by giving them a summary of the research findings and seeing how much sense it makes to them. Silverman (1993) has questioned the usefulness of this approach to credibility as it does not acknowledge the possible power difference between the researcher and the participant and cautions that participants may be more likely to agree with the account as a result of this. As the research was carried out by a health professional asking about experiences of the health service, this was a consideration, however despite this, it was still considered important to gain feedback in this way.

Confirmability or objectivity:

This concept relates to the openness of the research process and the extent to which the data collection and analysis can be scrutinised by someone outside the research process (Dey 1993; Miles & Huberman 1994). In order to enhance confirmability the steps in the research process should be documented. In this study a research diary detailing the decisions made at different stages of the research and samples of the analysis categories have been reproduced in the appendices. The interview transcripts are also available from the author.

Dependability or reliability:

This relates to the quality of the data analysis. The data were analysed by only one researcher (the author). In order to explore whether the data were coded into categories in a similar way by another person, a sample of quotes and categories was given to an independent rater. They were asked to group these under the category heading which they thought was most applicable. In terms of the qualitative paradigm, this is again a controversial aspect of trustworthiness (Silverman 1993). Inter-rater reliability is a concept from quantitative research and Silverman (1993) argues that it undermines the element of uniqueness which is expected from the philosophical, un-empirical qualitative stand-point.

Transferability or external validity:

Whilst generalisability is not a high priority in qualitative research, the degree to which it can be compared to other research in different settings is important (Miles &

Huberman 1994). In order for this to occur, the report of the study should be detailed enough to allow such comparisons to be judged.

Utility:

A good qualitative study should produce an account which generates further research questions and ideas for study (Henwood & Pidgeon 1995). As well as increasing knowledge, it should also provide information which can be used in the setting under study.

2.8 Ethical Approval:

Ethical approval was initially sought from two local research ethics committees. The first gave approval without any conditions. The second asked for additional measures to ensure that the group of people with dementia were not approached until it was certain that they met the inclusion criteria. The revised procedure was to first approach a family member (usually the person designated as their carer). They were asked if person had been told that they had dementia, whether they were able to remember this and whether they would want to talk about their experiences. If the person fitted these criteria, the family member was then asked to nominate a medical professional who was asked the same questions. The person with dementia was only approached after this. A third local research ethics committee was approached later in the process when recruitment difficulties were encountered. This committee approved the research unconditionally. Copies of consent forms and approval letters can be found in appendices six to ten.

2.9 Recruitment of participants:

For the pilot phase of the study, a voluntary service was approached through a community psychiatric nurse with regular input. Permission was given to present the research at a support group, and six people agreed to participate in the survey. One carer agreed to participate in an interview which became the first, pilot interview. The voluntary organisation felt that no-one with dementia whom they provided a service to would be able to participate.

For the main part of the study, a number of voluntary organisations and statutory services were approached. They were asked if they would distribute information packs to people with dementia and carers who were interested in participating and fitted the research criteria. The services approached are detailed in table one. All were willing to help, however, most services said that they only provided a service to people with moderate or severe dementia who would not meet the inclusion criteria. The three services who did agree to help recruit people with dementia were a voluntary service, a team of two consultant psychiatrists for the elderly and a community psychiatric nursing team. The latter team were only approached for recruitment of people with dementia when recruitment difficulties were apparent.

Service	People with dementia?	Carers?
ADS day service within a London borough.	No	Yes
ADS day service outside London.	Yes	Yes
CPN team for older adults #1	No	Yes
CPN team for older adults #2	Yes	N/A
Consultant Psychiatrist #1	Yes	Yes
Consultant Psychiatrist #2	Yes	Yes
Social services day centre within London Borough	No	Yes
NHS Day Hospital	No	Yes
NHS Day Hospital	No	Yes
Voluntary Carer Support Organisation	No	Yes

Table 1: Recruitment sources

Procedure for recruitment of people with dementia:

After the services who agreed to help were approached, they were given an explanation of the research and inclusion criteria. Two services felt there were potential participants, the voluntary service and an individual community psychiatric nurse. As both had ongoing contact with both the people with dementia and their carers they approached the carers with information about the research. If the carer agreed to participate, they were then contacted by the researcher and a meeting set up to discuss the study. The consent forms were completed at this stage. After consent had been established from a health professional a further meeting arranged to explain the research to the person with dementia and obtain their consent.

The results of the survey and their descriptive comments regarding how the

Procedure for recruitment of carers for the survey:

The purpose of the research was explained to carers who fitted the inclusion criteria. If they were interested in participating, they were given a survey which was returned anonymously to the researcher in a pre-paid envelope. To maintain anonymity,

participants were told that a report of the research would be available from the researcher and at the service through which they had been recruited.

Procedure for recruitment of carers for an interview:

All surveys included an information sheet and a return slip (appendix eleven) asking for volunteers for the interview. Those who agreed were then contacted by telephone and a meeting arranged to discuss the research.

2.10 Summary of recruitment:

Seventy-four surveys were given to carers. Of these, twenty-six were returned. Twelve carers agreed to participate in an interview. The first five were contacted and interviewed. No-one with dementia had been recruited during the period when carers came forward so a further two carers were contacted and interviewed. At the end of the recruitment period two people with dementia had been recruited.

3. Results:

The results of the survey and then the descriptive categories emerging from the accounts of people with dementia and carers will be presented.

3.1 Analysis of the survey:

A descriptive analysis of the survey data was carried out using SPSS for windows version 6 (Norusis 1993).

3.2 Demographic details of the survey participants:

Twenty-two women and four men returned the survey. Their ages of participants are presented in table 2. Relationship to the person being cared for are presented in table 3. Most participants were caring for a spouse or partner and one participant was caring for a friend of the family.

	Women n	Men n	Total n
Age:			
31-40	1	0	1
41-50	4	0	4
51-60	3	0	3
61-70	5	2	7
71-80	9	1	10
81+	0	1	1
Total:	22	4	26

Table 2 Age of participants

	Women n	Men n	Total n
Relationship:			
Spouse / Partner	15	4	19
Daughter or daughter-in-law	6	0	6
Other	1	0	1
Total:	22	4	26

Table 3 Relationship to person being cared for.

3.3 Demographic details of the people with dementia being cared for by survey participants:

The participants were caring for sixteen men and ten women. Details of their ages, impact of dementia, impact of other health problems and diagnosis given are presented in table 4.

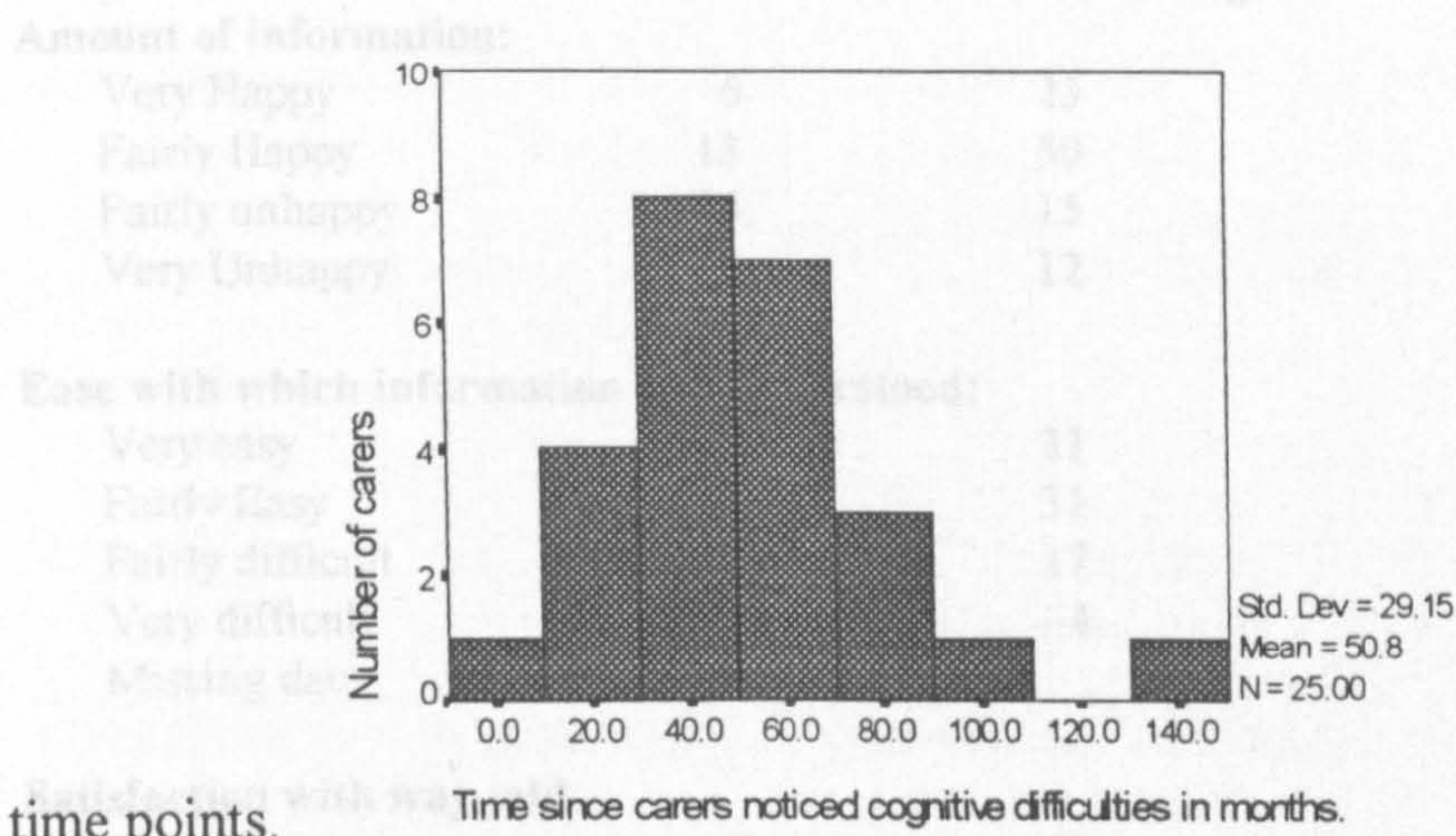
	Women n	Men n	Total n
Age:			
60-70	3	5	8
71-80	0	9	9
80 +	7	2	9
Total:	10	16	26
Impact of dementia:			
Mild	0	3	3
Moderate	3	5	8
Severe	7	8	15
Total:	10	16	26
Impact of other health problems:			
No impact	6	5	11
Mild	1	4	5
Moderate	2	4	6
Severe	1	3	4
Total	10	16	26
Diagnosis:			
Alzheimer's	6	10	16
Multi-infarct	1	1	2
Memory probs.	0	3	3
Senile dementia	2	1	3
Other	1	1	2
Total	10	16	26

Table 4: Demographic details of people being cared for by survey participants.

3.4 Time since diagnosis:

Participants were asked to estimate the time since they had first noticed changes or difficulties in the abilities of their relative and the time since diagnosis (see figures one

and two, below). There was a considerable range between participants across the two



time points.

Figure 1: Histogram showing of distribution of time since carers had noticed cognitive changes in the person being cared for.

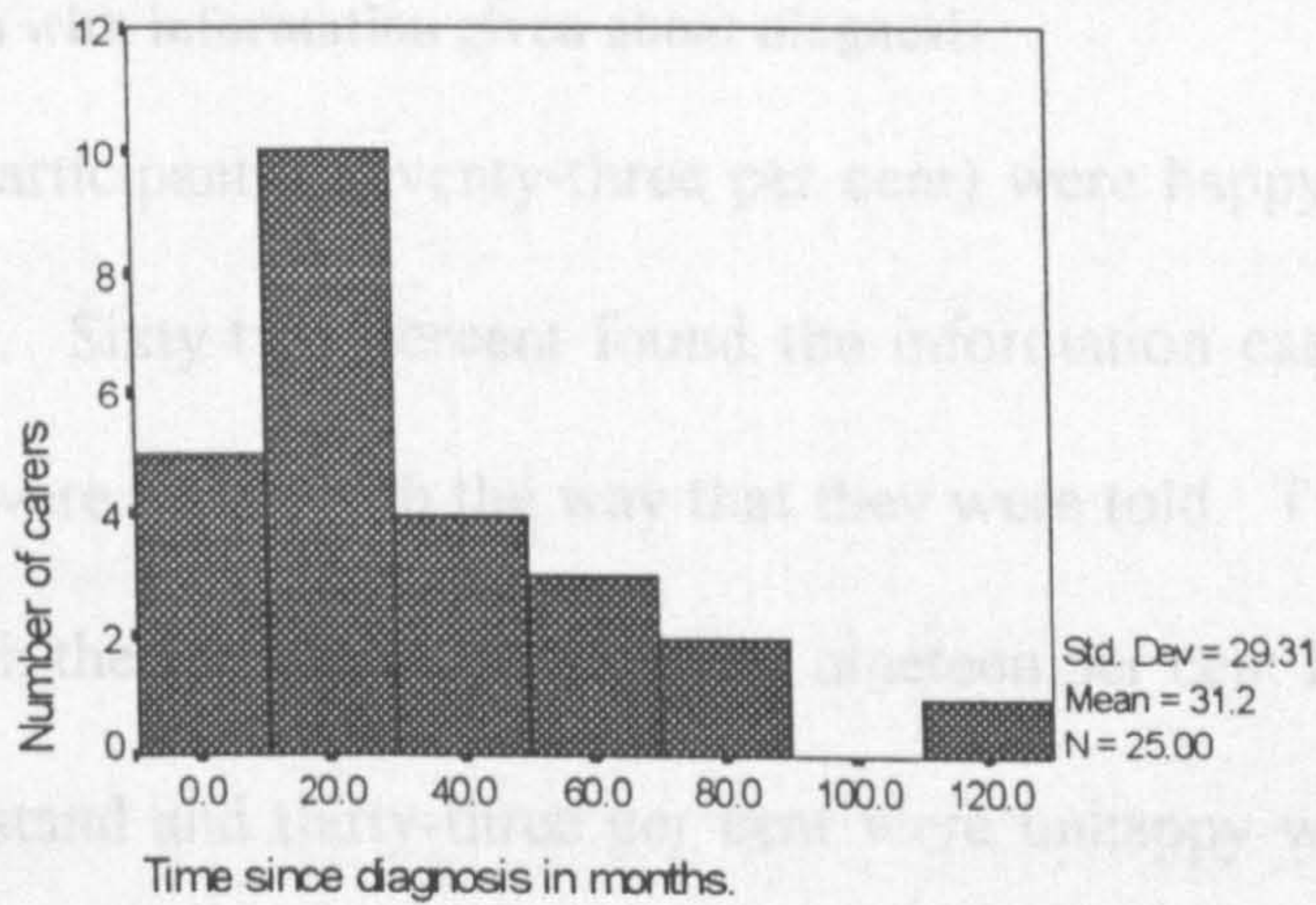


Figure 2: Histogram showing distribution of time since a formal diagnosis had been received.

3.5 Participants satisfaction with the information given about diagnosis:

The participants were asked three questions about their satisfaction with the information given at the time of diagnosis. This information is summarised in table 5.

	n	Percentage
Amount of information:		
Very Happy	6	23
Fairly Happy	13	50
Fairly unhappy	4	15
Very Unhappy	3	12
Ease with which information was understood:		
Very easy	9	31
Fairly Easy	9	31
Fairly difficult	4	17
Very difficult	1	4
Missing data	3	
Satisfaction with way told		
Very Happy	8	31
Fairly Happy	9	35
Fairly unhappy	3	12
Very Unhappy	6	23

Table 5: Satisfaction with information given about diagnosis

The majority of participants (Seventy-three per cent) were happy with the amount of information given. Sixty-two percent found the information easy to understand and sixty-six percent were happy with the way that they were told. Twenty-seven per cent were unhappy with the amount of information, nineteen per cent found the information difficult to understand and thirty-three per cent were unhappy with the way in which they were told.

3.6 Sharing information:

Participants were asked how much information the person they care for was given at the time the doctor gave a diagnosis and asked to estimate how much they felt the person actually understood (table 6). Fifty-eight percent felt that their relative had been given least some information and the remaining forty-three percent were given

none. No participant felt that their relative had understood all the information they were given and half felt that they had understood very little of what they were told.

How much information given:			How much information understood?		
	N	%		N	%
The same	2	8	All	0	0
Most	1	4	Most	2	10
Some	12	46	Some	5	25
None	11	43	Very little	13	57
			Missing data	6	

Table 6: Ratings by participants of the amount of information given to and understood by the person with dementia.

The participants were also asked who they felt made the decision about how much information to give to the person with dementia. This is summarised in table 7.

	N	Percentage
The doctor	4	17
The participant	5	22
The participant and family	1	4
The carer & the doctor	9	39
Other	4	17
Missing data	3	

Table 7: Who the participants felt made the decision about how much information to give.

The participants were also asked to rate how far they agreed with a general statement "A person with dementia should be given all the information about their diagnosis".

The levels of agreement with this question are presented in table 8.

	N	%
Agree strongly :	1	4
Mostly agree:	14	58
Mostly disagree:	2	9
Strongly disagree:	7	29
Missing data:	2	

Table 8: Level of agreement with statement about sharing,

3.6 Analysis of the interview transcripts:

Using the "framework" approach based on grounded theory described by Ritchie & Spencer (1994), the interview transcripts were analysed in several stages. Initially, one interview transcript in each group was reviewed to produce an preliminary list of codes which identified instances in the text related to the research questions. All the interviews were then reviewed and indexed using this list which was expanded and refined as new codes were added. This process was repeated a second time with the full index. The index was then listed onto a word processor and the passages of text indexed to each code were lifted from the text and grouped together. At this stage, the individual codes were grouped together into meaningful, related categories which described the data. Finally an account of the categories and the links between them was written using quotations from the text to illustrate particular points. The indexes of codes and categories for both sets of interviews can be found in appendices twelve to fifteen.

3.7 The interview participants: The people with dementia:

Jean was a seventy year old woman who had lived with her son and daughter-in-law for the previous year. Lorna, (her daughter-in-law), sat with her during the interview. Jean had come to stay with Lorna for a holiday, but had never returned home when they realised how much help she needed. Lorna told me that the difficulties had first been noticed three years before. After moving in with her son and daughter-in-law, she had seen a psychiatrist who had assessed her a few weeks before and told them that she had "Alzheimer's disease" and "senile dementia".

David was 63 years old. He lived with his wife. She sat in on the interview and provided most of the factual details. Alzheimer's Disease had been suspected for approximately three years after he had begun to have problems at work. A CT scan was taken and they were told that it showed some "brain shrinkage". His abilities deteriorated and his wife asked their general practitioner to send him to a large teaching hospital. After a magnetic resonance imaging scan was taken. He was then told that he had Alzheimer's disease. He was currently attending a day centre for two days each week.

3.8 Analysis of the interviews with people with dementia:

It was not possible to tape Jean's interview and the analysis is based on hand written notes taken during the interview. The categories which emerged from the data are presented in table 9.

Problems identified to cope with:	Ways of coping:	Contact with health services:
The losses The changes The potential for the family The lack of a cure The potential for deterioration	Fighting it Accepting it Thinking about the positives Expressing emotion Denial of the problem	General comments Positive experiences Negative experiences

Table 9: Categories emerging from interviews with people with dementia.

3.9 Problems identified to cope with:

The accounts given by Jean and David were painful and contained much about loss, change and worry about the future. Jean said "Now my brain is gone, I might as well be dead". She appeared to be grieving the loss of the "brilliant brain" and abilities she once had: "I can't see myself having it, that's the part that hurts". David said several times that he had felt "devastated" by the news. Jean said several times "It won't heal".

3.10 Ways of coping with dementia:

Jean and David seemed to have several ways of coping with their dementia. Both described what sounded like a struggle between fighting the dementia and accepting the situation. Jean said "I'm not going to let it beat me" and David "I just couldn't accept it". However, Jean also said "It won't heal, I have just got to accept it" and David "I was devastated when they said what it was, but what can you do about it".

They also talked about two more pro-active strategies. They both described how they held onto the positive aspects left: Jean said "The little girl [grand-daughter] keeps me going, I can do things for her". David also talked about how he could "let off steam" at the day centre: "We just discuss the condition really, gives us a chance to air our views, yes we do actually...we get caught in a discussion and just let all our steam off." There also seemed to be elements of denial of the seriousness of the situation as well. Jean said she would go home, although she had earlier said she knew she wouldn't, David said that there were times when he would rather not have been told, even though he would have known there was something wrong.

3.11 Views about contact with health professionals:

Only one positive comment was made about contact with health professionals. This was by David who said "I was happy that I was with my wife" when he was told. The other comments were negative. Jean said that she "couldn't cotton on to what they were saying at the time". She also had more questions that she wanted answers for: "I had a brilliant brain and I want to know what is wrong with it". David felt he had not had much support from his GP and seemed to feel dismissed. He said "I think that this is the problem, you know, If you have got this disease then they don't want to know and that upsets me"

3.12 The Interview Participants: The Carers:

Shona James was a 59 year old woman caring for her husband, Eric at home. Eric was 63 old. He had been given a diagnosis of Alzheimer's disease about ten months before the research interview. Eric had been sent to a consultant psychiatrist for the elderly by his GP. This consultant had ordered a physical examination and CT scan, from which the diagnosis was made. He had no other health problems. Shona was recruited through a voluntary organisation day care service.

Patrick Thomas was a sixty-two year old man caring for his wife Brenda at home. Brenda was 66 years old. She had been given a diagnosis of Alzheimer's disease about three months before the research interview. Brenda had been sent to a consultant neurologist by her GP who had carried out tests and a CT scan on which the diagnosis was made. She had no other health problems. Patrick was recruited through a social services day care centre.

Shona and Brian Hall were caring for Brian's mother Irene at home. Irene was eighty-nine years old. A diagnosis of dementia was made by the GP about three years before the research interview. They had subsequently had some contact with a community psychiatric nurse. Irene had never been referred to a consultant and had not had any further investigations to confirm the diagnosis. She had some other health problems including arthritis. Shona and Brian were recruited through a social services day care centre.

Ann Allen was caring for a friend of the family, Nina, at home. Nina was eighty-four years old. A diagnosis of Alzheimer's disease had been made after a referral to a consultant psychiatrist for the elderly about two years before the research interview. Nina did not attend any day care facilities. She had significant mobility problems and was partially sighted. Ann was recruited through a voluntary service which supported carers.

Evelyn Butler was caring for her husband Bob at home. Bob was 77 years old. A diagnosis of dementia had been made by a consultant psychiatrist for the elderly approximately three years before the research interview. Bob was partially deaf, but had no other health problems. Evelyn was recruited through a voluntary service which supported carers.

Moira Leighton was caring for her husband Clive at home. Clive was 74 years old. A diagnosis of Alzheimer's disease had been given by their GP after an assessment from a consultant approximately six months before the research interview.

Wendy Roberts was caring for her mother, Violet at home. Violet was 83 years old. A diagnosis of Alzheimer's disease had been given approximately three years previously when Wendy had taken her mother to the doctors for help with an unrelated problem.

3.13 The analysis of the interviews with carers:

The process of receiving a diagnosis:

During the course of the initial analysis, it became clear that when carers were asked about how they had been given the diagnosis, they saw the event as part of a much broader process of discovering that their relative had dementia. A decision was made

to present the analysis of this information to provide a context to the decision to share and contact with health professionals. Three themes emerged from the accounts given: **pre-diagnosis uncertainty; definition of a problem and hindsight.**

3.14 Pre-diagnosis uncertainty:

The accounts given by the seven people interviewed suggested some similarities in the process of diagnosis. They began with the person noticing that their relative was doing something unusual or uncharacteristic. For example,

"Well my husband went through a period of losing things, not knowing where he had put things. He has always been absolutely meticulous." [Moira]

"There were many things that happened which we all just laughed at. I mean we just didn't take much notice of, it wasn't in keeping with dad" [Evelyn]

Or they noticed a loss of skills such as reading, writing, driving, concentrating or following instructions:

"We went off abroad and it started, she didn't know her way around" [Patrick]

"We would go on holiday and I would say hang on a minute while I go in this shop, I'd come back and he would be nowhere to be seen." [Evelyn]

Emotional changes were also described including increased anxiety, depression and aggression:

"You would go in here [bedroom] first thing in the morning and she might be a sweet little old lady and within ten minutes, she would literally hit you. She would fist you." [Ann]

"He started getting very anxious about everything" [Moira]

Definition of a problem:

At first these changes were not enough to prompt a consultation with a doctor.

Evelyn, Shona and Wendy all said that they thought the problems were simply caused by ageing:

"There were many things which happened which we all just laughed at. I mean we just didn't take much notice of." [Evelyn]

"We'd say "Oh Dear! He's getting worse in his old age" [Shona]

"I mean, I forget things, and you just take it as a person getting older." [Wendy]

However, all reached a point at which these changes were redefined as a "problem", although this was not necessarily dementia. This point came either as the result of a crisis, or under the cumulative weight of the changes:

"Well my husband went through a period of losing things, not knowing where he had put things. He has always been absolutely meticulous about his paperwork. That's what he has done all his life and things would be put in the wrong place and then after a while he started getting very anxious about everything, money, worrying and all this. Lost and awful lot of weight and that is when I decided, that you know, suggested he went to the doctor" [Moir]

"We did go to the doctors. That's right, things were happening and she was getting us right irate. She was saying things, doing things and we were really getting...and in the end we said we couldn't stand it any longer because that's when we discovered we both had blood pressure, well high blood pressure" [Elsie & Brian]

As a result of consulting a doctor, a diagnosis of dementia was eventually given which. For Elsie & Brian and Shona this diagnosis gave them the benefit of hindsight that tied together many previous events:

"Certain things come to the front now that makes you think, well that could have been the start." [Elsie & Brian]

"When Eric lost his job, but we did feel prior to that, he was struggling. That it was developing for quite a few years. You can't always pin-point these things, can you?" [Shona]

For Shona and Ann it also confirmed their suspicions that it was dementia:

"I did diagnose it before the doctors even thought or gave me any indication" [Shona]

"I thought "It's got to be something". My sister was an avid reader, so I sent her to the library to get books and went through every book and we hit upon Alzheimer's disease ourselves" [Ann]

3.15 Sharing Information:

Elsie & Brian, Ann, Evelyn and Moira had been taken aside by a doctor or a Community Psychiatric Nurse and told the diagnosis alone. Wendy, Patrick and Shona had been with their relative when the diagnosis was first given. Evelyn and Moira had decided to share the information about diagnosis. The information relating to sharing generated three broad categories: **The influence of cognitive impairment; Openness** and **Protectiveness**. The latter two categories had a number of subsets relating to different aspects of the issue which are detailed in table 10.

Categories related to sharing information:	
The Influence of Cognitive Impairment	
Openness:	Protectiveness:
<p>"Facing the facts". Preserving and open relationship. Openness about wider issues. Challenging stigma.</p>	<p>Protecting the person from the "horrific details" in order to give hope. Perceptions about other people's protectiveness. Protecting the person from their mistakes. Previous experiences of protecting people from bad news.</p>

Table 10

3.16 Cognitive impairment:

Cognitive impairment is central to the difficulties presented by dementia and not surprisingly, it was raised by carers as a factor in determining how they handled information about diagnosis and prognosis. The practical consequences of the level of cognitive impairment had a large influence on the decision to share information about

diagnosis and prognosis. Patrick, Elsie & Brian, Wendy and Ann felt that the diagnosis had come "too late" and that the issue of sharing information was not relevant because their relative would not have understood. Typical comments included:

"No-one actually said because I don't think she could take it in" [Elsie & Brian]

"There was no way we could have told Nina. She would not have understood" [Ann]

The exception was Evelyn, who had decided to share some information. She commented that "It is all discussed. I know he won't remember it two seconds later.", suggesting that she tried to share information even though she was not sure it was understood by her husband.

3.17 Openness:

Facing the "bad news":

One of the positive consequences of sharing the information about diagnosis for Evelyn and Moira was that it gave their husbands the opportunity to "face up to" the problem:

"He knows he has got Alzheimer's disease, well I tell him that's what I call it, dementia, Alzheimer's disease, anything you like to call it. I said what you have got is jolly bad luck. If it wasn't you it might be me." [Evelyn]

"I knew that Clive would want to know. He would want to know you know in the same way I would like to know if I had anything terminal wrong with me. I would much rather face up to it and deal with it than to be in the dark and have people whispering and you know, I think that if you are a reasonably intelligent person, then you know what is going on, or that something is going on." [Moira]

The importance of maintaining an open relationship:

To not be open about the diagnosis would have placed Evelyn and Moira in a position of not maintaining what had previously been very open relationships with their husbands:

"Well Clive and I have never had any secrets amongst each other. We have been married 49 years and we have always been completely honest with each other." [Moira]

"I couldn't in all honesty keep something to myself without sharing it and also I know that Clive would want to know" [Moira]

Challenging stigma about dementia:

Evelyn felt strongly that being open about the diagnosis of dementia challenged some of the stigma surrounding the illness. She said she knew other people in the same position who had lost friends, but she and her husband had not. She felt that this was due to her openness:

"But I don't mind discussing all this, because it should be out in the open, shouldn't it. Because it's ... that's life isn't it. You have got to be able to communicate with people about good things and bad things just the same, really and it becomes acceptable. I mean everybody in the street knows he has a problem, but it doesn't bother them." [Evelyn]

Openness about wider issues:

Moira also talked about being open with her husband and friends about other, difficult issues such as death (from any cause):

"We talk among friends about dying because they have all got different things wrong with them and I say "Oh well! You know if I don't shoot him before.." that kind of thing, so in that way we have a very open relationship" [Moira]

3.18 Protectiveness:

Protecting the person from the "horrific details" in order to give hope:

The kind of information deemed unhelpful to share was different for each person. However, the consequences and prognosis of dementia were particularly singled out as being unhelpful to share with the person. It seemed that to share this information would have left the person without any hope at all for the future and that this would have had a negative impact on their quality of life.

For example, with hindsight Shona wished her husband had not been told the diagnosis because she felt he was now worrying about getting worse and had asked her whether he would:

"As it is now, yes, as it is now, I do feel I wished he had not been told because he is that bit younger, because if they'd have just said "You're suffering from depression", I'm wondering would he be coping better than he is now? Because I'm thinking he's beginning to look ill and drawn. Whether he's thinking to himself "How long have I got?" [Shona]

She also talked about subsequent questions that her husband had asked:

"Eric did say to her [OT] yesterday about the disease. "How will I end up?" and she looked at me as if to say "Have I got your permission? How do you feel?" And obviously she was a little bit apprehensive and she did say to Eric "You could stay like you are for some time, let's live day by day and don't worry about tomorrow, let's live day by day, when we get to that bridge we will all cross it together, you won't be going alone". She was so helpful and he seemed relieved at that. I looked at his face and I thought "She has given him hope." We know there isn't, but she has given him...he's got to live day by day and not worry what next year is going to bring" [Shona]

Evelyn and Moira both said that whilst they felt it important to be open about the diagnosis, the limit of this came at the point of sharing information about the future:

"She [doctor] took me on one side and told me in detail what all how it could get worse ... That was never said to him. I mean I don't say things to him that haven't happened, I mean I can't see much point really, can you?" [Evelyn]

"I have the Alzheimer's Disease Society newsletter, but I don't show it to Clive, because there are things in it that I know he would worry about. Hearing about what might happen in the future. And I think we have just got to take it from day to day otherwise it is stupid saying to somebody who can't fully understand, well you might lose your memory altogether and not be able to recognise your wife" [Moir]

Perceptions about other people's protective motives:

Related to the issue of sharing information with the person themselves were some observations that the amount of information received from the medical professions might also have been regulated by a desire to protect. Shona and Patrick made the following comments:

"Nobody has told me about the disease ... nobody ... and whether they are afraid because of Eric's age to put me in at the deep end, frighten me, I don't know. Perhaps they think that I might not be able to cope with it" [Shona]

"It is just that there is nothing they can do about it really. You think, you know, they look so good, they look great. There is nothing you can do about it. It's just a disease of the brain and your brain is dead. I suppose they don't want to tell you that, so they don't bother. Whether you want to know or not is another thing. You see, I had a bit of trouble myself, I had cancer, so I had a lot of pressure." [Patrick]

Protecting the person in other ways:

As with openness, the issue of protectiveness was also related to a wider context.

Shona described how she did not confront her husband when he had made mistakes in order to spare him from distress:

"I've marked my plugs "Do not turn off" because one weekend he turned off my freezer and I lost quite a lot of food, but I didn't tell him. I thought, no, I can't worry him, he's got enough to cope with" [Shona]

She also spoke of her wish to protect him from the undignified end which she feared for him:

"I've got to be honest. I love my husband dearly, but I hope that his span of life is not too long, so that he goes to the extreme of Alzheimer's disease. I'm not being wicked, no way, but I would like to be happy for him, so that he doesn't go into complete double incontinence, can't feed himself, can't see, can't hear. Already his hearing is not 100%. I would hate him to go on too long. I'd like that his life would ... enjoy his life now while it

has got quality. But when it gets that he has got no quality, I'd hope that his life would come to an end" [Shona]

Previous experiences of protecting people from bad news:

Ann had several previous experiences of close family members or friends becoming ill with cancer or dementia. Her account of not sharing the information about diagnosis and prognosis were strongly influenced by these experiences. Whilst she felt that Nina would not have understood the information, she said that she would probably not have told:

"There was no way we could have told Nina. She would not have understood. Erm...and also again, if we, if she had known in the early stages, I don't think I would have told her. Going back to what happened to her brother, two brothers and sister [all had killed themselves on entering residential care]. I wouldn't have told her. Not...because she couldn't cope with it, she would have taken her own life. You have to be very careful. [Ann]

"My mother knew what was wrong with her . She fought to the day she died. I had a friend who had stomach cancer at the age of 40. She knew what was wrong and she fought. When my father was told he had lung cancer, the day they told him he died. We brought him home from hospital and he wouldn't speak. He literally shut himself off and he was given six months to live and he died within eight weeks. And some people are like that, some people can cope and can fight back" [Ann]

3.19 Contact with medical services:

Participants were asked about their satisfaction with the contact with medical services such as GPs, Consultants and Community Psychiatric Nurses when they had consulted them and were given a diagnosis of dementia. These comments were divided into helpful and unhelpful. These categories are listed in table eleven.

Practical Support	Emotional Support
Helpful	Helpful
Advice, information and access to services. Timely response. Perceived competence of professionals.	Positive comments about overall service. Emotional support. Finding out what was wrong.
Unhelpful	Unhelpful
Lack of information and advice. Difficulty in accessing service. Perceived lack of competence.	The way in which the information was shared.

Table eleven: Categories related to contact with services.

"I mean she didn't leave us long after that, she stayed from when we first to her with depression." [Shona]

3.20 Helpful contact with services:

Overall satisfaction:

All the participants felt that the professionals they had contact with had been of some help. Those people who described the most positive experiences, commented on their overall friendly and pleasant approach:

"She was marvellous, our GP, absolutely marvellous" [Shona]

"Everybody was very charming and helpful and fell over backwards to be kind and pleasant" [Evelyn]

Practical advice, information and access to services:

Some positive comments were made by Shona, Elsie & Brian, Ann, Evelyn and Wendy about the practical advice and information received about the diagnosis and the services available to help. For example:

"He [consultant] said I'll give you all the information and he did. He gave me booklets of all the associations around, volcare, age concern, all the booklets" [Shona]

However, for Wendy, Ann and Evelyn, it was also helpful simply to be prepared for the future. Wendy and Ann summed this up:

"He prepared us for the fact that she would get worse but that there was nothing that they could do, no treatment or anything" [Wendy]

"Well I suppose that the most helpful thing was having it confirmed that what we suspected was true. Knowing, as I say, what you're up against, you can then think [pause] you can focus on it can't you. You can go and read up on it, or if there is anything on the radio, I will listen to it and see what I glean from other peoples' experiences" [Ann]

Timely response:

Patrick and Shona felt that when they consulted a doctor to find out what was wrong, the services responded quickly:

"I mean she didn't leave no longer than about three months from when we went to her with depression." [Shona]

"Then I went to the neurologist up there , he was pretty quick" [Patrick]

Emotional support:

For some people, the contact with doctors was seen as providing an emotionally supportive relationship. Shona, Elsie & Brian and Moira all commented on how much they valued reassurances given by the doctors that they could be contacted if new needs arose.

"Consultant gave me his secretary's number and said that if you need me at any time to talk, here's this number and you ring it and we are there for you. We are there for you when you need us" [Shona]

"If we wanted more help, I dare say, you know, he would offer to get it for us" [Elsie and Brian]

Perceived competence of professionals:

Feeling that the professionals were competent and knew their job was valued by

Shona, Patrick and Evelyn. Shona said that she had "confidence in that doctor" and

Patrick said of the neurologist "He was good, he knew his job".

3.21 Unhelpful contact with services:

Lack of information and support:

The most comments were made about the lack of information given at the time of diagnosis. There was a sense that the carers were left feeling that they were "on the edge" of what they needed to know. Furthermore, they all reported having found out more from other sources. In particular, it was information about the future which seemed to be missing. This was summed up by Shona, Patrick and Ann:

"Marvellous, can't fault it, really can't but it's just that they haven't gone into detail of how the disease progresses at the moment. I'm just toying on the outside of it, so I'm just on the outside of it, I'm not really getting into the in-depth side of Alzheimer's disease" [Shona]

"No, nobody says that. Nobody has ever sat down and told me that. Not that I suppose you really want to know. You might not want to know, some people want to know, others don't" [Patrick]

"I think if she could have sat down and explained what I was going to be up against" [Ann]

Only Evelyn felt she had been given enough information about prognosis, and this was from one consultant:

"But I mean, I didn't get what I would call any information. Nobody told me anything excepting DrX (consultant)." [Evelyn]

Difficulty in accessing services:

Patrick, Elsie & Brian and Evelyn had all struggled to gain access to what they felt were appropriate services when they wanted to find out what was wrong. Patrick's wife was first seen by a psychiatrist who he found unhelpful, while Evelyn had to ask specifically for her husband to be seen by a consultant. Elsie & Brian was told by the GP that her mother-in-law would be sent an appointment with a consultant, but this never arrived because he was too busy. Patrick described this as if he were:

"Struggling to get into the system" [Patrick]

Dissatisfaction with the way in which they were told about dementia:

Shona, Patrick and Ann and Evelyn all felt dissatisfied with the way in which they were told about dementia and the level of support they received at the consultation. Shona felt she was not given an opportunity to decide what she wanted:

"I wished that they had taken their time and asked the family, had us together and said to my daughter and myself "Your father has got Alzheimer's disease. Do you want him to be told? Or would you like us not to tell him and just let you cope with it on your own? I think I would have liked some time to have thought about that, but it happened so quickly, I don't think they even thought about how it would affect us as a family and effect Eric knowing. I don't think that we were given the opportunity to decide" [Shona]

Patrick and Ann felt there was no opportunity for them to ask questions after the initial shock had worn off and that information was given or services offered was given without adequate explanation:

"Well. I suppose that it's that much of a shock and a worry to you, you don't know what you were told really. I can't remember everything I've been told" [Patrick]

"It would have been nice to have somebody sit down and discuss it, perhaps not so much then, but if somebody came back say a week later, saying now you have thought about it, are there any questions, do you still want to keep her at home? What kind of support do you need? Perhaps after you have got over the initial shock." [Ann]

Ann also felt that the consultant had been very "brusque" with her because she had decided to keep Nina at home, against her advice.

Perceived lack of competence:

Just as the carers valued the perceived competence of the professionals, they did not find it helpful when they felt them to be less than competent. For example by not sending reports, giving out-of-date information:

"They sent me over to a psychiatrist who couldn't make head nor tail of her" [Patrick]

"I was given a sheet which turned out to be out of date information, all the phone numbers were wrong" [Ann]

4. DISCUSSION:

The design and methodologies used in the present study will be discussed to place the results of the survey and the outcome of the qualitative analyses in context. Each research question will then be discussed and the findings of this study will be related to the theoretical background to diagnosis in dementia. Finally, implications for future research and clinical practice will be discussed.

4.1 The design of the study:

Overall, the use of both a quantitative and a qualitative method to explore the research questions was useful. In particular, the complexity of the diagnosis process, the small number of people with dementia recruited and the potential for distress to arise in the course of asking about such a sensitive area confirm that a qualitative approach is an appropriate way to investigate this area.

The survey sample was small. However, the majority of the carers who completed the survey were women caring for a husband, mother or mother-in-law. This reflects findings in previous research that women make up the majority of carers of family members with dementia (Woods 1995) which is significant for the generalisability of the findings to a wider population of carers. Of the people being cared for with dementia, the majority had Alzheimer's disease reflecting the relative incidence of Alzheimer's disease and other forms of dementia. The ages of the people being cared for were evenly spread across the three age ranges (60 to 70, 71-80 and 81+).

However, the ratio of men to women was very different in the latter two categories. All those aged between 71 and 80 were men but of those aged over 81, seven out of nine were women. It is not clear why there were no women between 71 and 80, but the lower life expectancy for men might mean that fewer have survived to the 81+ category. It was also not possible to control for some factors such as psychological difficulties and physical health difficulties of carers which might have influenced their responses. With hindsight, question D in the survey which asked for level of agreement with an overall attitude could have been expanded to also ask about satisfaction with the decision made by the individual carer rather than a general statement.

4.2 Recruitment strategies:

The success of the recruitment strategies used was mixed. The response rate for the survey was around 35 percent. A number of people who did not want to participate in the survey said that they were under too much pressure already without adding another task. It is possible that this was the case for those people who agreed to take a survey but then did not return it, but this remains as speculation. The majority of those who did complete a survey said that they found it very easy and were very happy with the way they had been approached to take part. Once the participant had filled in a survey, several agreed to an interview. This would appear to be a successful strategy for recruitment to the interviews. As with most other research not enough information is available to compare those who did and did not volunteer, leaving a potential source of bias.

It proved extremely difficult to recruit people with dementia who met the inclusion criteria. Two specific difficulties were encountered. The first was that the majority of the services used for recruitment said that they only provided a service to people with moderate or severe dementia who could not participate. The second recruitment problem related directly to the issue of sharing information and will be returned to later in the discussion. An alternative recruitment strategy to reach larger numbers of people might have been to advertise nationally through the Alzheimer's Disease Society. Another might have been in conjunction with a pharmaceutical trial where presumably a diagnosis has been shared in order to obtain informed consent, although this would possibly produce a very biased sample of people who were coping with their condition in a very pro-active way.

4.3 Issues affecting the reliability and validity of the survey findings:

It proved difficult to recruit only people who had been given a diagnosis in the last year. The time range was extended, but this has implications for the validity of the findings as length of time since diagnosis may have an independent influence on satisfaction. Questions A4 and B3 failed to give and valid information about ethnic origin and had to be disregarded. This was unfortunate as this would have added important information about the sample. With hindsight categories should have been provided for carers to choose from.

A further difficulty became apparent after conducting the qualitative interviews. This was that even when asked a specific question, the carers did not make a firm distinction between what information they received at the time of the diagnosis and what they had received since unless prompted to distinguish the two. Clearly, they could be confused in the survey responses where there was no opportunity to clarify whether this was the case. This could account for the unexpectedly high levels of satisfaction which were obtained. The high levels of satisfaction could also have been obtained because the source of the research was clearly a health-led initiative and they carers felt wary of being critical despite promises of anonymity

4.4 The "Trustworthiness" of the qualitative interviews:

Each of the components of trustworthiness will be discussed in relation to the outcome of the qualitative interviews. The account provided by the qualitative interviews aimed to be a valid account of the experiences of the two groups rather than a reliable account generalisable to all people with dementia or caring for a person with dementia.

Credibility, transferability and utility:

The reader must decide for themselves how far the qualitative part of the research has any "rhetorical power" in describing the experiences of a group of people with dementia and a group of carers. Judgements about the transferability of the study are also implicit in the information presented about it. The utility of the research is addressed in the final sections of the discussion on implications for future research and clinical relevance.

In order to check the credibility of the analysis from the point of view of the carers, they were asked to comment on a summary of their own interview and the factors found to be helpful and unhelpful by the whole group. The summary relating to the whole group and a sample of the individual feedback can be found in appendices sixteen and seventeen. Three carers returned comments which are reproduced in appendix eighteen. All agreed with the summary and one person added further comments and corrected a factual inaccuracy.

Dependability:

In this study, the data analysis was carried out only one researcher and represents an account unique to the interaction of that researcher and the people interviewed. The dependability of the analysis was checked by having a second person re-sort the quotes used in the into the categories. The percentage agreements found are presented in table twelve.

	Percentage agreement:
Categories related to sharing information:	
Protecting the person from knowledge of their illness at all	100%
The importance of maintaining an open relationship.	100%
The influence of cognitive impairment on the decision to share.	70%
Facing up to the illness	33%
Categories related to helpful contact with services:	
Timely service from health professionals:	100%
Emotional support from health professionals:	67%
Perceived competence of the health professionals:	25%
General comments about positive experiences:	25%
Advice, information and access to services:	14%

Table 12: Inter-rater reliability.

The percentage agreements have a wide range. Those related to helpful aspects of contact with professionals were particularly problematic. A major problem was mixing the quotes from the category "general comments about positive experiences" and "perceived competence of professionals". This suggests that these categories were not as dependable as those for sharing. A further refining of the helpful categories could take place in a further round of data collection.

Confirmability:

The main criteria for ensuring confirmability of any qualitative research is to have the research process open to scrutiny. As well as the indexes of codes and categories, a research diary is included (appendix nineteen) detailing the decisions made over the course of the research in both the development of the research and the analysis of the information obtained. The original interview scripts are also available from the author.

4.5 Discussion of results:

In this section each of the research questions will be dealt with in turn. The outcome of the current research will be related to previous research findings. As the qualitative interviews provided a great deal of information which has already been presented, this will not be repeated.

(1) What are the experiences of a small group of people with dementia of their condition?

Recruitment difficulties resulted in only two interviews. However, using a qualitative approach, it was possible to provide some information about the issues raised for the

participant by having dementia and the ways that they had found to cope with it. As in the literature relating to coping with other terminal illnesses, Joan and David seemed to be trying to gain some kind of acceptance of their situation. The issues that David and Joan seemed to be struggling with were to accept the possibility of future deterioration; that there was no cure; that their families would have to support them and the loss of a sense of self without their memory rather than their physical death.

Some information was also gathered about the kind of coping styles adopted by Joan and David to cope with having dementia. There were some elements of denial of the seriousness of the situation, but which were very difficult to untangle from the memory impairment present. However, there were also some more pro-active strategies similar to those identified by Harrison & McGuire (1994) and Watson (1994) for people with cancer. For example, concentrating on the positive and finding a place to express emotion and gain support. Although not explicit in the interviews, it is also possible that taking part in the current research and David's participation in a pharmaceutical trial also represent pro-active coping strategies.

(2) How satisfied were this group with the way in which they were given information about the dementia?

David and his wife were clearly unhappy with their contact with health professionals, except that David appreciated his wife being with him when the diagnosis was given. David's assertion when talking about his general practitioner that "The problem is you know, when you have got this disease they just don't want to know, and that upsets me" echoed the finding by Iliffe (1995) that a number of carers feel general practitioners do not provide adequate support. An obvious

drawback with Jean's account was that because of her memory impairment, she could not remember enough about of her contact with doctors to say whether she was satisfied or not.

(3) What proportion of carers were satisfied with the amount of information they received at the time their relative was diagnosed with dementia?

Nearly three quarters of the survey carers were happy or very happy with the amount of information received at the time of diagnosis. This is an unexpected finding. Previous research had suggested that carers thought the information they received was too vague and that they were generally dissatisfied with the response of health professionals (Brodaty *et al.* 1990, Iliffe (1995). As raised in the discussion of the design, survey respondents could have been commenting on all the information received at different stages, not specifically what they obtained from health professionals at the point of diagnosis. The high levels of satisfaction could be accounted for because information from non-professional sources was included in their judgement. This was viewed more positively by the carers interviewed when they were prompted to distinguish the two. A number of factors could account for this, for example that it was obtained later in the process and carers were more able to understand it; that it was presented in a different form, such as books and newsletters or that the relationship between the carer and a non-professional organisation was such that they could ask for more information or questions about what they had received.

(4) What proportion of carers were satisfied that the information they received was easy enough to understand?

The survey results suggested that information given to carers at the time of diagnosis was generally easy to understand. Some 62 percent of the sample thought the information they were given was easy or very easy to understand. As with the previous question, this is a surprising finding given the complexity and variability of the illness concept described by Arendt & Jones (1993) and Gubrium (1986; 1987). What was not addressed was the relationship between the amount of information and the ease with which it could be understood. The high levels of satisfaction could reflect that the information was easy to understand simply because it was so sparse.

(5) What proportion of carers were satisfied with the way in which they were given the information?

Sixty-six percent of the carers who filled out the survey were happy with the way in which they were told about their relative's diagnosis. These levels of satisfaction are higher than found by Brodaty *et al.* (1990) who found that only 46 percent of carers were happy with the way that they were told. The same caution applies to this finding, that carers may not have wished to criticise the health professionals in a piece of health-related research.

(6) What proportion of carers shared information they were given about dementia with person they care for?

Only twelve percent of people being cared for by the carers were given the same or mostly the same information at the time of diagnosis. A majority of 46 percent were

given some information and 43 percent were given none. This is comparable to the finding of Brodaty *et al.* (1990) that 39 percent of people with dementia being cared for by their sample had not been given any information. However, it is much lower than the 80 percent found by Husband (1996) and the 90 percent in the unpublished data reported by Rice & Warner (1995). Regardless of amount of information given, nearly two thirds of the people being cared for were rated as having little or no understanding of the information at the time it was given supporting the idea that cognitive impairment had progressed to a level beyond which the person could not understand the information before it was given.

(7) How much information do carers feel a person with dementia should be given?

Thirty-eight percent of carers disagreed with the statement that a person should be given all the information about their diagnosis and 58 percent mostly agreed. No carer said that they strongly agreed with this statement. Wolff *et al.* (1995) found that one third of general practitioners in their sample and one fifth of psychiatrists were unsure whether a person with dementia should be given their diagnosis.

(8) If sharing information with the person was an issue, what are the factors identified by the group which influenced their decision to share or not share information about diagnosis with the person they care for?

The carers who were interviewed expressed the ethical dilemma that they found themselves in. This was between being open with the person and protecting them from the seriousness of the situation. Some similarities can be drawn with previous research by Husband (1996). She also found that information was not shared

because the carer thought the person should be protected from the implications of knowing; that information was not shared because the person would not be able to understand the information and that information was shared in order to maintain an open relationship.

Receiving an actual diagnosis was part of a much longer process for the carers. On a practical level, the degree of cognitive impairment at the time a diagnosis was given meant that sharing information never became an issue for some. However, when sharing was an issue, the people interviewed seemed to place themselves on a continuum between the need to be open with the person and the need to protect them from the negative consequences of knowing. The position on this continuum appeared to be where the carer had found a balance between these two needs and to be influenced by a number of factors such as the nature of the previous relationship with the person or previous experiences of illness. The openness and protectiveness was applicable to wider issues. Of particular note was the role of information about future deterioration, which seemed to be managed very sensitively and the explicit need of some carers to maintain a sense of hope for the person about the future regardless of the reality.

(9) What are the factors identified by the group of carers as helpful and unhelpful in their contact with services at the time their relative received a diagnosis of dementia?

This question was answered using information from the qualitative interviews. In the feedback, one of the participants commented that the helpful and unhelpful contact "just about equal each other out". The factors which were perceived as

helpful if they were present were by and large judged to be unhelpful if they were absent. Two broad dimensions of support which emerged from the analysis were "Practical support" and "Emotional support" suggesting that both are important to carers at the time they receive information about a diagnosis. What also emerged from the interviews, but were incidental to the research questions were the many positive comments which were made about information and support subsequently received from other, non-medical sources such as the Alzheimer's Disease Society and voluntary agencies.

4.6 Conclusions:

The present study presents some preliminary information about the research area. The implications of the results of this study for the two explanations put forward in the introduction will be discussed. The first was that communication about dementia between health professionals, people with dementia and carers and between carers and the person with dementia could be influenced by the ill-defined and uncertain illness concept of dementia. Both the results of the survey and the accounts of carers of the diagnosis process suggested that an important reason for not sharing information was that it would not have been understood by the person at the time the diagnosis was made. This would suggest that for some people, the complexity of a diagnosis does mean that it is only given when all other possibilities have been ruled out and that this may be too late for the person to understand the information. However, it is still not possible to know how whether a diagnosis was not shared because of a lack of certainty or through a wish to protect the person from the consequences of being given a tentative diagnosis at an earlier stage.

The high levels of satisfaction found in the survey with the information given at the time of diagnosis suggest that despite the complexity and uncertainty of the illness concept described by Arendt & Jones (1992) and Gubrium (1986), information was being presented in a useful way. However, this is a tentative suggestion because of the likelihood that the survey data was unreliable. The interviews with carers suggested that information about the course of the illness was not given which could indicate that the variability of prognosis in dementia made information particularly difficult for health professionals to present.

The second explanation was that communication about dementia was made particularly difficult by the nature of dementia as an emotionally painful and devastating illness involving the loss of a sense of self. The hopelessness of the situation could lead to a wish to protect the person from the consequences of knowing about their condition. Kitwood (1993) and Sinason (1992) have implied that in dementia there is a wish to believe that "ignorance is bliss" by not acknowledging the emotional impact of dementia on the person themselves. They suggested that this is part of an unconscious wish on the part of people without dementia to protect themselves from their own fears and the overwhelming emotional pain that might be expressed by the person with dementia. It was suggested that this created a situation where a diagnosis of dementia was not given both to protect the person from the full emotional consequences of knowing and also a way of being self-protective.

The information from the survey confirmed that most people with dementia being cared for by the sample of carers did not receive as much information as the carers themselves. There was also some indication from the survey and the carer interviews that when cognitive impairment did not prevent understanding, the flow of information was controlled with the explicit purpose of protecting the person. The extent of information shared varied, but an important theme was to maintain a sense of hope for the person, sometimes regardless of the situation. This was summed up by a comment on a survey:

"My husband has got dementia. He does not know and why should he? I keep telling him he is going to get better to give him something to hold on to. look after him 24 hours a day. It is hard work, but when you love someone you get on with it"

Protectiveness was a theme which was repeated throughout the process of conducting the research. The carers said they were protecting the people they cared for. Some carers felt that the doctors might be protecting them from knowledge and some staff approached in the recruitment process were explicit that people with dementia should never be told to protect them. The issue of protectiveness was difficult to avoid even in the research process. It would have been useful to check the credibility of the account of sharing information with the carers who were interviewed. However, the process of analysis suggested that decisions were made to protect or be open on the basis of a personal value system and each person had chosen the "right" decision for them. There was a concern that sending an summary with accounts of different or contradictory decisions might have a negative impact for some participants, so it was not included.

The extent to which such protectiveness of people with dementia reflects a need for self-protection on the part of people without dementia remains a matter of speculation. The research interviews with people with dementia suggest some parallels with the way that people cope with other terminal illnesses, although much more work needs to be done to understand how cognitive impairment influences this. Joan and David both spoke of a struggle to accept their condition. It is still an open question as to whether knowing or not knowing information makes a difference to the way in which people cope with dementia.

4.7 Implications for future research:

Much more research needs to be carried out into the way that people with dementia make sense of and cope with their experience of the illness. Given the cognitive impairment present in dementia, it is important to understand which coping strategies are related to positive outcomes, how this differs from other illnesses, what are the immediate and long-term implications for psychological well-being on sharing or not sharing information and who is most likely to be able to make use of such information in a positive way.

Further interviews and information could be gathered to build on the accounts already obtained. This could then be used to extend the qualitative account and move towards a more comprehensive grounded theory of the issues of protectiveness and openness raised for carers. The methodology could also be used to extended research into the views of health professionals of sharing information in

dementia and whether they see the issues as different in dementia as a result of the presence of cognitive impairment. This should include clinical psychologists and the way in which the results of any cognitive assessments carried out by clinical psychologists as part of the diagnosis process are shared with the person. The survey information about satisfaction with information at the time of diagnosis could be extended and collected at or soon after participants have contact with health professionals to improve reliability of the information.

4.8 Clinical implications:

It is likely that increased knowledge and awareness of dementia and more sophisticated assessment techniques such as magnetic resonance imaging, that dementia will be diagnosed earlier (Woods 1995). The way in which sharing of information is dealt with in dementia could become more and more relevant for clinical psychologists in their work with people with dementia, their families and services. The current research highlights how sharing information could be a source of potential conflict between the needs of people with dementia and their carers, and one which clinical psychologists should be aware as interventions will usually involve working with both. The implications of knowing about any terminal illness also raise issues of suicide, assisted suicide and informed consent to medical procedures which should be explored in specifically in relation to dementia.

Sinason (1992) comments that "Ignorance is not bliss. But neither is knowledge".

There are indications that being given information about dementia does result in

psychological distress for the person as they have to come to terms with its consequences. Clinical psychologists are well placed to meet the needs of people with dementia by providing support and a psychological understanding of the way individuals can negotiate and cope with their situation. Clinical psychologists can also contribute to the wider system of dementia care services and the needs of staff who work closely with the emotional impact of dementia.

References:

- Arendt & Jones (1992). Epidemiology of dementia. In Jones, J.M.M. & Miesen, B.M.L. (1992) (Eds.) Caregiving in dementia: Research and Applications. London: Routledge.
- Bell, L. (1995) To tell or not to tell? Alzheimer's Disease Society Newsletter. May, p.4.
- Brodaty, H., Griffin, D. & Hadzi-Pavlovic, D. (1990) A survey of dementia carers: Doctors' communications, problem behaviours and institutional care. Australian & New Zealand Journal of Psychology. Vol. 24, pp. 362-370.
- Brody, H. & Tomlinson, T. (1988) Commentary on "Truth telling and Alzheimer's Disease". The Journal of Family Practice. Vol. 26, No. 4, pp. 404-406.
- Bryman, A. & Burgess, R.G. (1994) Developments in qualitative data analysis: an introduction. In Bryman, A. & Burgess, R.G. (1994) Analyzing Qualitative Data. London: Routledge.
- Charlton, R.C., (1992) Breaking Bad News. The Medical Journal of Australia. Vol. 157, No. 2, pp. 615-619.
- Cotrell, V. & Schulz, R., (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. The Gerontologist. Vol. 33, No. 2, pp. 205-211.
- De Lepeleire, J., Heyrman, J., Baro, F., Buntinx, F. & Lasuy, C. (1994) How do general practitioners diagnose dementia? Family Practice Vol. 11, No. 2, pp. 148-152.
- Dey, I. (1993) Qualitative Data: A user-friendly guide. London: Routledge.
- Elliott, R (1994) Rigor in Psychotherapy Research: Questions in search of appropriate methodologies. Paper presented at the meeting of the Society for Psychotherapy Research, York, England.
- Erde, E.L., Nadal, E.C. & Scholl, T.O. (1988) On Truth Telling and the diagnosis of Alzheimer's disease. The Journal of Family Practice. Vol. 26, No. 4, 401-406.
- Faulkner, A., Maguire, P. & Regnard, C. (1994) Breaking Bad News - A Flow Diagram. Palliative Medicine. Vol. 8, pp. 145-151.
- Ford, S., Lewis, S. & Fallowfield, L. (1995) Psychological morbidity in newly referred patients with cancer. Journal of Psychosomatic Research Vol. 39, No. 2, pp. 193-202.
- Gubrium (1986) Alzheimer's and Oldtimers: The descriptive organisation of senility. Greenwich, CT: JAI Press.
- Gubrium, J.F. (1987) Structuring and destructuring the course of illness: the Alzheimer's disease experience. Journal of the sociology of health. Vol. 23, pp.1-22.
- Gubrium, J.F. (1992) Qualitative research comes of age in gerontology. The Gerontologist Vol. 32, No. 5, pp. 581-582.

- Gubrium, J.F. & Sankar, A. (1994) Qualitative Methods in Ageing Research. Sage: London.
- Haring, B. (1974) Medical Ethics St. Paul Publications: Slough.
- Harrison J. & McGuire P. (1994) Predictors of psychiatric morbidity in cancer patients. Journal of Mental Health Vol. 165, pp. 593-598.
- Henwood, K.L. & Pidgeon, N.F. (1995). Grounded theory and psychological research. The Psychologist. March, pp.115-118.
- Homer, A.C., Honavar, M., Lantos, P.L., Hastie, J.R., Kellett, J.M. & Millard, P.H. (1988) Diagnosing Dementia: Do we get it Right? British Medical Journal Vol. 297, pp. 894-896.
- Husband, H. (1996) Sharing the diagnosis: How do the carers feel? Journal of Dementia Care. Jan/Feb., pp. 18-20.
- Iliffe, S., Booroff, A., Gallivan, S. Goldenberg, S., Morgan, P. & Haines, A. (1990) Screening for cognitive impairment in the elderly using the mini-mental state examination. British Journal of General Practice. Vol. 40, pp. 277-279.
- Iliffe, S. (1994) Why GPs have a bad reputation. Journal of Dementia Care. Nov./Dec., pp. 24-25.
- Iliffe, S. (1995) Early detection and management of "confusion". in "crises" - The role of primary care workers. Paper given to the joint workshop of the Alzheimer's Disease Society, the British Geriatrics Society, the Royal College of Psychiatrists and the Research Unit of the Royal College of Physicians. October 19th 1995.
- Iliffe, S. (1995a) How well do GPs communicate with Patients? Alzheimer's Disease Society Newsletter. March, p. 4.
- Jones, R. (1995) Why do qualitative research? British Journal of Medicine. Vol. 311, p. 2.
- Jutagir, R. (1994) Psychological Aspects of Aging: When does memory loss signal dementia? Geriatrics Vol. 49, No. 3, pp. 45-52.
- Keady, J., Nolan, M. & Gilliard, J. (1995) Listen to the voices of experience. Journal of Dementia Care. May/June, pp. 15-17.
- Kendrick, K. (1994) Ethics in practice: Truth Telling in Clinical Practice. Professional Nurse. Vol.67, pp. 36-43.
- Killick (1994) Using writing with people with dementia. Dementia research unit: University of Stirling.
- Kitwood, T. (1990) The dialectics of dementia: With particular reference to Alzheimer's disease. Ageing & Society. Vol. 10, pp. 177-196.
- Kitwood, T. (1993) Person and Process in Dementia. International Journal of Geriatric Psychiatry. Vol. 8, pp. 541-545.

- Kitwood, T. (1995) Positive long-term changes in dementia: Some preliminary observations. Journal of Mental Health. Vol. 4., pp. 133-144.
- Mason, J. (1994) Linking qualitative and quantitative data analysis. pp. 89-110. In Bryman, A. & Burgess, R.G. (1994) Analyzing Qualitative Data. London: Routledge.
- Miles, M.B. & Huberman, M.A. (1994). Qualitative Data Analysis: An Expanded Sourcebook. (2nd Edition). Sage Publications: Thousand Oaks.
- Norusis, M.J. (1993) SPSS for Windows Manual (Version 6.0). SPSS inc: Chertsey.
- Patton M.Q. (1987) How to use qualitative methods in evaluation. (2nd ed.). Sage: London.
- Rice, K. & Warner, N. (1994) Breaking the Bad News: What do Psychiatrists tell patients with dementia about their illness? International Journal of Geriatric Psychiatry. Vol., 467-471.
- Rice, K. & Warner, N. (1995) How much do psychiatrists tell their patients? Alzheimer's Disease Society Newsletter. July 1995.
- Ritchie, J. & Spencer, L. (1994) Qualitative data analysis for applied policy research. pp. 173-195. In Bryman, A. & Burgess, R.G. (1994) Analyzing Qualitative Data. London: Routledge.
- Rossor (1993) Alzheimer's Disease. British Medical Journal Vol. 307, pp. 779-782.
- Sinason (1992). Mental Handicap and the Human Condition: New Approaches from the Tavistock. London: Free Association Books.
- Silverman, A. (1993) Interpreting Qualitative Data: Methods for analysing talk, text and interaction. London: Sage.
- Strauss, A. & Corbin, J. (1990) Basics of Qualitative Research: Grounded Theory Procedures and Techniques. London: Sage.
- Tobiansky, R. (1994) Understanding Dementia: The Clinical Course of Dementia. Journal of Dementia Care. Sept/Oct, pp. 26-28.
- Watson, M. (1994) Psychological care for cancer patients. Journal of Mental Health. Vol. 3, pp. 457-465.
- Wolff, L.E., Woods, J.P. & Reid, J. (1995) Do general practitioners and old age psychiatrists differ in their attitudes to dementia. International Journal of Geriatric Psychiatry. Vol. 10, pp. 63-69.
- Woods, B. (1995) Dementia Care: progress and prospects. Journal of Mental Health Vol. 4, pp. 115-124.
- World Health Organisation (1992) The ICD-10 classification of mental and behavioural disorders. WHO: Geneva.

INDEX TO APPENDICES:

1.	Information sheet for survey.....	80
2.	Survey Questionnaire.....	82
3.	Information sheet for carer interview.....	88
4.	Information sheet for interview for people with dementia.....	90
5.	Interview schedule for participants with dementia.....	92
6.	Interview schedule for carers.....	94
7.	Consent form for interview.....	96
8.	Form filled in by carers to allow person with dementia to be approached for an interview.....	97
9.	Consent form filled in by health professional to allow a person to be approached with dementia to be approached for an interview.....	98
10.	Approval letters from research ethics committees.....	99
11.	Form asking for interview participants.....	104
12.	Index of codes for analysis of interviews with people who have dementia.....	105
13.	Analysis categories and transcript quotes for interviews with people who have dementia.....	106
14.	Index of codes for analysis of interviews with carers.....	108
15.	Analysis categories and transcript quotes for interviews with carers...	111
16.	General feedback to carers for respondent validity.....	121
17.	Sample of individual feedback to carers for respondent validity ¹	124
18.	Feedback from participants.....	125
19.	Research diary.....	126

¹ It was not possible to include all the feedback to carers. A sample has been included and the rest are available from the author on request.

[survey]

INFORMATION SHEET

"Being given a diagnosis of dementia: The experiences of people with dementia and of people who care for someone with dementia."

PURPOSE:

I am a psychologist completing my final year of clinical training. During this year, I have the opportunity to carry out research in an area which is of interest to me. I am therefore, carrying out this research to find out about the experiences of people who care for somebody with dementia when that person was given their diagnosis. I hope that the information gathered from this research will increase our understanding of how to provide better support for people who care for somebody with dementia.

WHAT YOU WILL BE ASKED TO DO:

If you would like to participate in this study, you will be asked to fill in a short questionnaire. The questionnaire asks about your own experiences of being told about the dementia.

YOUR RIGHTS AS A PARTICIPANT IN THIS RESEARCH:

Your participation in this research is voluntary. If you do not want to take part, this will in no way affect the services which you receive. You have the right to withdraw from the study at any time. Simply tell me that you no longer want to continue, or do not return the questionnaire.

Your answers to the questions will be anonymous and your name will never appear in the report of this research. In August 1996 a summary of the research findings will be available from me if you would like to know what has been learned.

Thank you very much for your co-operation. Please fill out the questionnaire and return it in the pre-paid envelope.

I would also like to talk to carers about their experiences in more depth. This will involve an interview of about an hour which would take place at your home or other convenient location. If you would be willing to talk to me, please read the information sheet and then fill in your name, address and a contact telephone number on the enclosed form and return this with the questionnaire.

[Name and title of researcher]

 **[Address]**

 **[Telephone number]**

SURVEY QUESTIONNAIRE

Please read each question carefully and tick one box for each question. The survey is anonymous.

[A] Information about you:

[A1] What is your relationship to the person that you care for?

- Spouse / partner
 - Daughter
 - Son
 - Sister
 - Brother
 - Other (Please specify)
-

[A2] Are you male or female ?

[A3] How old are you?

- 20 or younger
- 21-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71-80
- 80 or older

[A4] What is your ethnic origin?

[B] Information about the person you care for:

[B1] Are they male or female ?

Please turn over.

[B2] How old are they ?

- 60-70
- 71-80
- 80 or older

[B3] What is their ethnic origin?

[B4] At present, how much care does the person need?

- The dementia only mildly affects their day-to-day life. For example, they need some help with planning the day and remembering to do things.
- The dementia interferes with day-to-day life. They need a fair amount of help with complex living skills such as cooking and managing finances.
- The dementia interferes a great deal with day-to-day life. They need help with simple living skills such as washing, dressing, eating and continence. They have care 24 hours a day because of the dementia.

[B5] Do they have any physical health problems?

- No health problems.
- Physical health problems which do not interfere with day-to-day life.
- Physical health problems which interfere slightly with day-to-day life.
- Physical health problems which interfere a great deal with day-to-day life.

Please turn over.

What are their main physical problems?

[C] Finding out about dementia:

[C1] Approximately how long ago did you begin to notice the dementia?

[C2] Approximately how long ago was this confirmed as dementia by a doctor or other health professional?

[C3] What did they tell you was wrong?

- Alzheimer's disease
- Multi-infarct dementia
- Vascular dementia
- Memory problems
- Senile dementia
- Other (Please specify)

[C4] How satisfied are you with the amount of information that they gave you?

- Very Happy
- Fairly Happy
- Fairly Unhappy
- Very Unhappy

Please turn over.

[C5] How easy was it to understand the information they gave you?

Very Easy

Fairly Easy

Fairly Difficult

Very Difficult

[C6] Overall, how satisfied were you with the way that you were told?

Very Happy

Fairly Happy

Fairly Unhappy

Very Unhappy

[C6] How much information was the person you care for given at the time the doctor told you what was wrong?

The Same

Most

Some

None

If the person was given the same information please go to question [C8].
If the person was not given the same information (for example, you were told more than them by the doctor) please answer the following question:

[C7] Who decided what information to give them?

The doctor

You

You and other members of your family

You and the doctor

Other (Please specify)

[C8] How much do you feel the person you care for understood the diagnosis when it was given to them?

All

Most

Some

Very Little

Please turn over.

[D] Opinions about how much information to give:

How much do you agree with the statement that “A person with dementia should be given all the information about their diagnosis”?

Agree Strongly Mostly Agree Mostly Disagree Disagree Strongly

[E] Please use this space to write down any other information you would like to give about the way that you were told about the diagnosis of dementia. I would be very happy to hear about anything you feel is not covered by the questions above.

Please turn over.

Evaluation:

It would be very helpful to know what you thought of this survey:

How easy was it to complete?

Very Easy

Easy

Difficult

Very Difficult

How happy were you with the way you were asked to take part in this project?

Very Happy

Fairly Happy

Fairly Unhappy

Very Unhappy

If you were unhappy, please say why:

Any other comments about the survey?

Thank you for completing the survey.

[carer interview]

INFORMATION SHEET

"Being given a diagnosis of dementia: The experiences of people with dementia and of people who care for someone with dementia."

PURPOSE:

I am a psychologist completing my final year of clinical training. During this year, I have the opportunity to carry out research in an area which is of interest to me. I am therefore, carrying out this research to find out about the experiences of people who care for somebody with dementia when that person was given their diagnosis. I hope that the information gathered from this research will increase our understanding of how to provide better support for people who care for somebody with dementia.

WHAT YOU WILL BE ASKED TO DO:

If you would like to participate in this study, I will interview you for approximately one hour. During this time I will ask you questions about your own experiences and feelings about being told about the dementia. The interview will be tape-recorded so that I can have an accurate record of what you have told me. It would be helpful to have your comments on a written summary of your interview a few days afterwards. This will help me to make sure I have understood what you have told me.

YOUR RIGHTS AS A PARTICIPANT IN THIS RESEARCH:

Your participation in this research is voluntary. If you do not want to take part, this will in no way affect the services which you receive. You have the right to withdraw from the study at any time. Simply tell me that you no longer want to continue. Any information you have given up to this point can be destroyed and not used in the final report if you so wish.

Your answers to the questions will be anonymous. Your name will never appear in the report of this research. Please ask me at any time if you have questions about the research. In August 1996 a summary of the research findings will be available from me if you would like to know what has been learned.

Thank you very much for your co-operation. If you would be willing to participate in this research, please read and sign the enclosed consent form.

Rachel Taylor
Psychologist in Clinical Training

✉ **Clinical Psychology,**
Salomons Centre,
David Salomons Estate,
Broomhill Road,
Southborough,
Tunbridge Wells,
KENT.
TN3 0TG

[interview with person with dementia]

INFORMATION SHEET

"Being given a diagnosis of dementia: The experiences of people with dementia and of people who care for someone with dementia."

PURPOSE:

I am a psychologist completing my final year of clinical training. During this year, I have the opportunity to carry out research in an area which is of interest to me. I am therefore, carrying out this research to find out how people experienced being given a diagnosis of dementia. I hope that the information gathered from this research will increase our understanding of how to provide better support.

WHAT YOU WILL BE ASKED TO DO:

If you would like to participate in this study, I will interview you for approximately one hour. During this time I will ask you questions about your own experiences and feelings about being told that you had dementia and the way in which you were told this. The interview will be tape-recorded so that I can have an accurate record of what you have told me. It would be helpful to have your comments on a written summary of your interview a few days afterwards. This will help me to make sure that I have understood what you have told me.

YOUR RIGHTS AS A PARTICIPANT IN THIS RESEARCH:

Your participation in this research is voluntary. If you do not want to take part, this will in no way affect the services which you receive. You have the right to withdraw from the study at any time. Simply tell me that you no longer want to continue. If you so wish, any information you have given up to this point can be destroyed and not used in the final report.

Your answers to the questions will be anonymous. Your name will never appear in the report of this research. Please ask me at any time if you have questions about the research. In August 1996 a summary of the research findings will be available from me if you would like to know what has been learned.

Thank you very much for your co-operation. If you would be willing to participate in this research, please read and sign the enclosed consent form.

Rachel Taylor
Psychologist in Clinical Training

✉ **Clinical Psychology,**
Salomons Centre,
David Salomons Estate,
Broomhill Road,
Southborough,
Tunbridge Wells,
KENT.
TN3 0TG

Semi-structured Interview Schedule for People With Dementia.

.....The interview will begin by reading out the following

Purpose of the research:

Thank you for agreeing to take part in this research. I am interviewing a group of people who have dementia. I would like to find out more about your experiences of being told about the dementia. I am in the final year of clinical psychology training and have the opportunity to carry out a piece of research in an area of interest to me.

I hope that the information will enable health care staff to better understand the needs of people who have been through this experience.

Consent:

Please read again the information sheet and consent form and ask me any questions about the research before we begin.

You may tell me at any stage that you would like to withdraw from the interview. This will not affect your right to the services you need. I would also like your consent to send a brief letter to your GP simply informing them that you have consented to this interview.

Consent given ?

Yes / No

.....Time to read information sheet and consent form

1. Do you have any questions?

Background Information:

1. How old are you?
2. How long have you known about your illness?
3. How did you find out about it?
5. What were you told about it to begin with?
6. What were you told would happen in the future?
7. How did you feel when you were told?

Satisfaction:

1. How helpful did you find the information?
2. How happy are you with the way that you were told?
3. What was most helpful about what you were told?
4. What was least helpful?

..... At the end of the interview the following will be read out

Thank you for participating in the research.

Now we have finished, how are you feeling about the questions I have asked you?

Was there anything in the interview which particularly upset or bothered you?

Do you have any questions you would like to ask me?

Is there anything you feel that I have not asked you about that you feel is important?

Is there any information about services in this area that I could send you?

I would like to send you a short summary of this interview to read in the next few days. It would help me be sure that I have understood what you have told me. I would be grateful if you would read it and send it back in the pre-paid envelope with your comments.

Thank you again for your help.

..... End of Interview

Semi-structured Interview Schedule for People who Care For a Person With Dementia.

.....The interview will begin by reading out the following

Purpose of the research:

Thank you for agreeing to take part in this research. I am interviewing a group of people who care for a family member who has dementia. I would like to find out more about one particular area. This is your experience of being told about the dementia. I am in the final year of clinical psychology training and have the opportunity to carry out a piece of research in an area of interest to me.

I am also interviewing a group of people who are in the early stages of dementia to find out what their experiences are of being told about their illness.

I hope that the information will enable health care staff to better understand the needs of people who have been through this experience.

Consent:

Please read again the information sheet and consent form and ask me any questions about the research before we begin.

You may tell me at any stage that you would like to withdraw from the interview. This will not affect your right to the services you need. I would also like your consent to send a brief letter to your GP simply informing them that you have consented to this interview.

Consent given?

Yes / No

.....Time to read information sheet and consent form

1. Do you have any questions?

Background Information:

1. How old is your relative?
2. What is your relationship to them?
3. How long have you known about their illness?
4. How did you find out about it?
5. What were you told about it to begin with?
6. What were you told would happen in the future?
7. How much did you know about dementia before?

Satisfaction:

1. How helpful did you find the information?
2. How happy are you with the way that you were told?
3. What was most helpful about what you were told?
4. What was least helpful?

Sharing the Information:

1. Does your relative know what is wrong with them?
2. At the time that you were told what was wrong with them, what was the person themselves told?
3. How much of the information do you think that they understood at the time?
4. Who decided how much to tell them?
5. What were the things that were taken into account in making this decision?
6. Are you happy with what they were told?

..... At the end of the interview the following will be read out

Thank you for participating in the research.

Now we have finished, how are you feeling about the questions I have asked you?

Was there anything in the interview which particularly upset or bothered you?

Do you have any questions you would like to ask me?

Is there anything you feel that I have not asked you about that you feel is important?

Is there any information about services in this area that I could send you?

I would like to send you a short summary of this interview to read in the next few days. It would help me be sure that I have understood what you have told me. I would be grateful if you would read it and send it back in the pre-paid envelope with your comments.

Thank you again for your help.

..... End of Interview

CONSENT FORM

I.....(Name)

of.....(Address)

.....(Telephone Number)

hereby fully and freely consent to participate in the research project entitled:

"Being given a diagnosis of dementia: The experiences of people with dementia and of people who care for someone with dementia."

I have been given an information sheet, which I have read and understand, and which I can keep for further reference. I understand that I may withdraw my consent at any stage in the investigation and that this will not affect my right to receive the services I need.

Signed.....

Date.....

I confirm that I have explained the nature and effect of this research procedure to the participant and that their consent has been given freely and voluntarily.

Signed.....(Researcher)

Date.....

I.....(Name)

of.....(Address)

am aware of the content of the research project entitled:

"Being given a diagnosis of dementia: The experiences of people with dementia and of people who care for someone with dementia."

and believe that:

.....(Name)

of.....(Address)

understands that she/he has dementia and would be able to participate in a research interview. The person named below is a health professional who knows the person and I am happy for you to contact them to confirm that they know about their diagnosis of dementia and would be able to participate in the interview.

Name, address and position of health professional:

.....

.....

Signed.....

Date.....

I.....(Name)

.....(Position)

am aware of the content of the research project entitled:

"Being given a diagnosis of dementia: The experiences of people with dementia and of people who care for someone with dementia."

and believe that:

.....(Name)

of.....(Address)

understands that she/he has dementia and would be able to participate in a research interview.

Signed.....

Date.....

WEST KENT HEALTH AUTHORITY



Preston Hall, Aylesford
Kent ME20 7NJ
Tel 01622 710161
Fax 01622 719802

18th April 1996

Rachel Taylor
Psychologist in Clinical Training
Clinical Psychology Training Scheme
Salomons Centre
Broomhill Road
SOUTHBOROUGH
Kent, TN3 0TG

Dear Ms. Taylor,

"BEING GIVEN A DIAGNOSIS OF DEMENTIA: THE EXPERIENCES OF PEOPLE WITH DEMENTIA AND OF PEOPLE WHO CARE FOR SOMEONE WITH DEMENTIA"

PROTOCOL NO. 1496 (Please quote in all correspondence)

Thank you for submitting the amendments as requested by the Tunbridge Wells Local Research Ethics Committee.

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study whose title is given at the head of this letter. I am therefore happy to give you our approval on the understanding that you will follow the protocol as agreed.

It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given.

If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, a revised protocol should be submitted to the Committee.

Covering DARTFORD & GRAVESHAM • MAIDSTONE • MEDWAY • TUNBRIDGE WELLS

Chairman: Peter Edgley Chief Executive: Ruth Carnall

You will no doubt realise that whilst the Committee has given approval for the study on ethical grounds, it is still necessary for you to obtain approval from the relevant Clinical Directors or Chief Executive of the Trust in which the work will be done.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of results is sent to the Secretary in due course.

Yours sincerely

S. H. Adams

PP T.G. WILLIAMS
CHAIRMAN
TUNBRIDGE WELLS LOCAL RESEARCH ETHICS COMMITTEE

BEXLEY LOCAL RESEARCH ETHICS COMMITTEE

221 Erith Road
Bexleyheath
Kent DA7 6HZ

Tel: 0181 308 3206
Fax: 0181 301 3842

Our Ref: AB

19 January 1996

Ms Rachel Taylor
South Thames Regional Clinical Psychology Training Scheme (East)
Salomons Centre
David Salomons Estate
Broomhill
Tunbridge Wells
Kent

Dear Ms Taylor

**Re: BEING GIVEN A DIAGNOSIS OF DEMENTIA: The Experiences of
people with dementia and of people who care for someone with dementia'**

I am writing to advise you that at the meeting of the Bexley LREC held today, the Committee granted full approval to the above protocol.

Yours sincerely



Ann Butler (Mrs)
Secretary - Bexley LREC



LOCAL RESEARCH ETHICAL COMMITTEE

Ms R. Taylor
Psychologist in Clinical Training
Salomon's Centre
David Salomon's Estate
Broomhill Road
SOUTHBOROUGH
Tunbridge Wells TN3 0TG

6th June 1996

Dear Ms Taylor

Re: **Being given a diagnosis of Dementia: The experiences of people with dementia and people who care for somebody with dementia**

At its meeting on Thursday 6th June 1996, the District Ethical Research Committee agreed that there were no ethical objections to the proposed study detailed at the head of this letter.

The Committee wishes to hear of the progress and outcome of the study and wishes to be advised in advance of any significant proposed deviations from the original protocol and would expect to be informed of any unusual or unexpected results which raise questions about the safety of the research.

The ethical approval for this study is given for twelve months from the date of this letter. If a project fails to start within this time, it will be necessary to contact the Chairman of the Ethical Research Committee to find out whether it is necessary to re-apply for ethical approval.

We wish to remind you that the Ethical Committee gives ethical approval only and it is your responsibility to seek the Management's approval to the relevant NHS bodies, before the project takes place.

Yours sincerely,

Dr Richard Price
Chairman

"Being given a diagnosis of dementia: The experiences of people with dementia and of people who care for someone with dementia."

I would be willing for you to contact me to take part in an interview for the above research project.

Name:.....

Address:.....

.....

.....

Telephone Number.....

Signed:.....

Date:.....

Index of codes and preliminary categories for interviews with people with dementia:

- 1. Problems identified to cope with:**
 - 1.1 The losses.**
 - 1.2 The changes.**
 - 1.3 The potential burden for family.**
 - 1.4 The lack of a cure.**
 - 1.5 The potential for deterioration.**

- 2. Ways of coping:**
 - 2.1 Fighting it.**
 - 2.2 Accepting it**
 - 2.3 Thinking about the positives.**
 - 2.4 Expressing emotion about it.**
 - 2.5 Denial of the problem.**

- 3. Contact with health services:**
 - 3.1 General comments.**
 - 3.2 Positive experiences.**
 - 3.3 Negative experiences.**

Appendix thirteen:

Problems identified to cope with:	
Losses:	"I never thought I would end up like this" [Jean] "I feel lost" [Jean] "Now my brain is gone, I might as well be dead" [Jean] "I had a brilliant brain" [Jean] "Before that I could do anything" [Jean] "I was devastated" [David] "It was so upsetting really" [David]
Changes:	"At first I thought it could have been blood pressure, or something like that" [Jean] "It was uncanny, I couldn't explain it" [Jean] "I was losing things. It wasn't me" [Jean] "When you have thought for yourself" [Jean] "I had to have a pad by the phone" [Jean] "I can't see myself having it, that is the part that hurts" [Jean]
Potential burden on family:	"I worry about it, they [family] have all the responsibility" [Jean]
Lack of a cure:	"It won't heal" [Jean]
Possible deterioration in the future:	"you can't get rid of it" [Jean]
Ways of coping:	
Fighting it:	"I'm not going to let it beat me" [Jean] "I won't accept it, I know" [Jean] "I just couldn't accept it" [David]
Accepting it:	"It won't heal, I have just got to accept it" [Jean] "I would like a scan. I would accept it better if I had that. It would give me more satisfaction in myself" [Jean] "Is he [son] accepting it, because I'm going to have to" [Jean] "I was devastated when they said what it was, but what can you do about it?" [David]
Thinking about the positives:	"The little girl [grand-daughter] keeps me going, I can do things for her" [Jean] "I'm glad I'm here with my family" [Jean] "I like going over to [day centre] because most of us have got it there, you know and I just enjoy the staff their" [David]

<p>Expressing emotion about it:</p> <p>Index of codes and preliminary groupings</p> <p>1. The influence of cognitive impairment</p>	<p>"We just discuss the condition really, gives us a chance to air our views, yes we do actually, you know, that's what we usually do, we get caught in a discussion and just let all our steam off" [David]</p>
<p>Denial of the situation:</p> <p>1.2. Their general level of cognitive</p> <p>2. Not telling the person their diagnosis</p> <p>3. Not telling the person their prognosis</p> <p>3.1. Because there is no hope</p> <p>3.2. Because she is not past the point yet occurred.</p>	<p>"When I go back home" [Jean] - said after she had also clearly said she knew she could not go home.</p> <p>Do you get times when you wish you hadn't been told? "Yes I do actually". Wife repeats question: would you rather know you have got Alzheimer's disease? "No" [firmly] "I would rather I didn't know, that is what I am trying to say" Wife: "But you would know you had something wrong with you anyway?" "Yes"</p>
<p>Contact with health services:</p>	
<p>Positive comments:</p>	<p>"I was happy I was with my wife" when they gave diagnosis [David]</p>
<p>Negative comments:</p> <p>5. Protection of other people</p> <p>5.1. From the doctor</p> <p>5.2. From the diagnosis</p> <p>6. Previous experience of the</p> <p>6.1. Had experience of the</p> <p>7. Facing up to the</p> <p>7.1. Telling</p>	<p>"I couldn't cotton on to what they were saying. I'd love to know. You go to the doctor and they don't satisfy you. I had a brilliant brain and I want to know what is wrong with it. What causes it" [Jean]</p> <p>Did you feel doctors were helpful? "No not really" [David]</p> <p>"No-one asked whether you wanted to know or no information like that." [David]</p> <p>"I think that this is the problem you know, If you have got this disease then they [GP] don't want to know, and that upsets me" [David]</p>

Appendix fourteen:

Index of codes and preliminary grouping into categories used for carer interviews:

1. The influence of cognitive impairment on the decision to share:
 - 1.1 Memory problems specifically mean person cannot understand.
 - 1.2 Their general level of cognitive impairment mean person cannot understand.
2. Not telling the person their diagnosis.
3. Not telling the person their prognosis:
 - 3.1 Because there is no hope.
 - 3.2 Because there is not point in telling the person about things which have not yet occurred.
4. Perception of protection by others:
 - 4.1 Because of relatively young age or carer.
 - 4.2 Because of the stress it could cause carer.
 - 4.3 Because of stress carer is already under from their own ill-health.
5. Protection in other ways:
 - 5.1 From their mistakes.
 - 5.2 From the indignities of the future.
6. Previous experience of giving bad news:
 - 6.1 Bad experiences of other family members.
7. Facing up to the illness:
 - 7.1 Telling the person so that they can face up to it.
8. Importance of an open relationship:
 - 8.1 Carrying on regardless.
 - 8.2 Not having secrets.
 - 8.3 The person would know what was happening anyway.
9. Openness about wider issues:
 - 9.1 About dying.
 - 9.2 About other things, good and bad.
10. Challenging stigma:
 - 10.1 Dementia should be talked about.
11. Possibilities other than dementia:
 - 11.1 Old age.
 - 11.2 Stress.
 - 11.3 Depression.
 - 11.4 Brain tumour.
 - 11.5 Anxiety.

12. Working out that it was probably dementia:
 - 12.1 Narrowing it down to dementia.
13. Changes in and loss of abilities:
 - 13.1 Losing practical skills.
 - 13.2 Getting lost.
 - 13.3 Forgetting to do things.
14. Emotional changes:
 - 14.1 Becoming aggressive.
 - 14.2 Becoming anxious.
 - 14.3 Becoming depressed.
15. Hindsight:
 - 15.1 Being able to look back and see when it started more clearly.
16. Critical incident which prompted the consultation which resulted in a diagnosis of dementia:
 - 16.1 Crisis Point
 - 16.2 Slower accumulation of changes.
17. Helpful advice, information and access:
 - 17.1 Information about other services.
 - 17.2 Being told what they would be up against.
 - 17.3 Access to services.
18. Timely service:
 - 18.1 Assessments arranged quickly.
19. Perceived competence of professionals:
 - 19.1 Feeling that the professionals knew their job.
20. Unhelpful aspects of advice and information:
 - 20.1 No information about prognosis and the future.
 - 20.2 Not enough information about anything.
21. Access to services:
 - 21.1 Difficulty getting access to relevant people:
22. Perceived lack of competence:
 - 22.1 Not feeling understood by professional.
 - 22.2 Feeling that the professional could not give bad news sensitively.
 - 22.3 Not passing on information or giving wrong information.
23. General, positive comments about contact.
24. Unhelpful lack of emotional support:
 - 24.1 Feeling it was just a job to the professional.

24.2 Feeling unsupported when disagreements over care raised.

25. The way in which the news was given:

25.1 Wanting to have more time to talk about sharing information.

25.2 Not being able to remember what was said.

25.3 Feeling that the person with dementia was dismissed.

25.4 Wanting a second chance to ask questions.

The pre-diagnosis process:	
Overlap of other possibilities and dementia:	<p>"We'd say "Oh dear!, he's getting worse in his old age" [Shona]</p> <p>"We thought it was stress at work" [Shona]</p> <p>"We realised it was more than just depression" [Shona]</p> <p>"Well, I blamed depression, but obviously he was depressed, but also there was this problem creeping in with the depression." [Shona]</p> <p>"I thought it might be a brain tumour" [Elsie & Brian & Brian]</p> <p>"We were told it was all down to this background, the worry of this move" [Ann]</p> <p>"He had been put on anti-depressants" [Evelyn]</p> <p>"He started getting very anxious about everything" [Moira]</p> <p>"[GP] gave him prozac. We'd heard of it and I said would this help with the depression, because he had an awful lot of depression with this anxiety" [Moira]</p> <p>"I mean, I forget things and you just take it as a person getting older I think" [Wendy]</p>
Working out that it was probably dementia:	<p>"I did diagnosis it before the doctors even thought or gave me any indication" [Shona]</p> <p>"For about a year ... I said, I'm sure he's got Alzheimer's disease" [Shona]</p> <p>"I thought, it's got to be something ... my sister was an avid reader, so I sent her to the library to get books and went through every book and we hit upon dementia, Alzheimer's disease ourselves" [Ann]</p>
Changes in and losses of previous abilities:	<p>The deterioration in his memory, his ability to drive, his ability to hold a conversation" [Shona]</p> <p>"My daughter used to say "Dad's driving, Mum! Isn't it awful! What's the matter with him?" [Shona]</p> <p>"We went abroad ... and it started. She didn't know her way around and that, and she used to be looking, you know at the places and didn't know her way around" [Patrick]</p> <p>"She had loads of change in her purse. I presume she couldn't put up the 55p, she was giving a pound all the time or a fiver" [Patrick]</p> <p>"She lost a lot" [Patrick]</p> <p>At the opticians "On the last check-up, in July 1993. When she first had it (cataract operation) done in June, she could read the chart quite well, when we went at the end of July 1993, I was horrified because when she looked at the chart, the specialist said read it down and she started off, the first two or three lines all right and then it was absolute rubbish" [Ann]</p> <p>"She wasn't eating. I mean I'd started feeding her because I thought it was laziness, but she'd say "Oh! I forgot that my food was there"" [Ann]</p> <p>"In the end, she couldn't sign her own name, couldn't read, she used to love to read" [Ann]</p> <p>"There were many things that happened which we all just laughed at. I mean we just didn't take notice of, it wasn't in keeping with Dad" [Evelyn]</p> <p>"I mean we would go on holiday and I would say hang on a minute</p>

had blood pressure as well, high blood pressure." [Elsie & Brian & Brian]

"So this is in December 1993 and I called the doctor out. And I said to her well, she had got a sore mouth and I said to her, you're obviously run down, so I'll get the doctor out and while he was there I said to him we have really got a problem, I cannot cope with her tempers" [Ann]

"Anyway, in April 1994, the cat we had at the time had an accident and had to be out to sleep. Now, her reaction was as if nothing had happened. Now when our old cat died two years before that, she was hysterical, so we knew then that we had a real problem. We started ringing the doctor" [Ann]

"And in the end, I was feeding her and food was coming out the side of her mouth and she was choking on just a drink and I got the doctor out again and he said, "Oh I think we ought to get Dr X (consultant psychiatrist), so I said yes, well something is going wrong, because to my mind she was dying. I ended up making four phonecalls to the surgery, in the end Dr X came out and she had got haloperidol poisoning. I didn't realise with her legs, but when she did the reflex test, there was nothing, and what it was doing in fact was working on her throat muscles and paralysing them" [Ann]

"I don't know why, I have no idea why at all, but for some, unknown reason, he quite suddenly thought he had got cancer of the stomach or something. I had no idea why. And it was from that moment that we went to the GP eventually and said perhaps he could be checked out and it was that check-out in fact" [Evelyn]

"Well, my husband went through a period of losing things, not knowing where he had put things. He has always been absolutely meticulous about his paperwork. That is what he had done all his life, and things would be put in the wrong place and then after a while, he started getting very anxious about everything, money, worrying and all this. Lost a lot of weight. And that is when I decided that you know, suggested that he went to the doctor" [Moir]

"We were there for something else" [Wendy]

PRACTICAL SUPPORT

Helpful:

Advice information and access:

"He's put me in the right direction" [Shona]

"He [consultant] said "I'll give you all the information. And he did. He gave me booklets of all the associations around, vol-care, age concern, all the booklets to read." [Shona]

"Well I suppose that the most helpful thing was having it confirmed that what we suspected was true. Knowing, as I say, what you're up against, you can then think [pause] you can focus on it can't you. You can go and read up on it, or if there is anything on the radio, I will listen to it and see what I glean from other peoples' experiences" [Ann]

"She [consultant] is the only person actually who took me on one side and said "Now this doesn't get any better. It can only get worse" sort of thing, and all the horrific things you can expect, and all that. And I said "Well I'm not bothered" so I said "What will be will be" and that's it you see, it doesn't truly bother me, erm she was the most in-depth." [Evelyn]

	<p>while I go in this shop, and I would come back and he would be nowhere to be seen" [Evelyn]</p> <p>"And then all this repeating and all sorts of things like that" [Evelyn]</p> <p>"Well, my husband went through a period of losing things, not knowing where he had put things. He has always been absolutely meticulous about his paperwork" [Moirira]</p> <p>"Things would be put in the wrong place" [Moirira]</p> <p>"She sort of started going like it, forgetting things and that kind of thing" [Wendy]</p>
<p>Emotional Changes:</p>	<p>"Starting to get aggressive, verbally aggressive, not physical, but verbally aggressive, erm, couldn't go anywhere without me" [Shona]</p> <p>"Things were happening and she was getting us right irate. She was saying things, doing things and we were really getting..." [Elsie & Brian & Brian]</p> <p>"She was getting sudden flare-ups of temper, we would walk into the room and say I'm doing this and she would just go mad and her temper would fly and another time she reduced me to tears one day because I think I was busy packing and she just went up the wall. Her language was appalling, she called me all the names" [Ann]</p> <p>"You would go in there first thing in the morning and she might be a sweet little old lady and within ten minutes, she would literally hit you, fist you." [Ann]</p> <p>"She had got to the stage where I'd be through here in the kitchen and she would be calling me non-stop" [Ann]</p> <p>"He started getting very anxious about everything" [Moirira]</p> <p>"[GP] gave him prozac. We'd heard of it and I said would this help with the depression, because he had an awful lot of depression with this anxiety" [Moirira]</p>
<p>Hindsight:</p>	<p>"When Eric lost his job, but we did feel prior to that he was struggling. That it was developing for quite a few years. You can't always pin-point these things can you?" [Shona]</p> <p>"But little did we know that this was developing" [Shona]</p> <p>"She lost a lot, had it for a long time and I did not notice it at all" [Patrick]</p> <p>"It seemed to come on her pretty quick, but maybe we just didn't notice" [Patrick]</p> <p>"Certain things come to the front now that makes you think, well that could have been the start" [Elsie & Brian & Brian]</p> <p>"Sitting and thinking about it, there has been a problem for at least ten years" [Ann]</p>
<p>Critical incident or point reached which prompted a decision to consult a health professional:</p>	<p>"But it wasn't until he was made redundant two and a half years ago that things started to go wrong. We realised it was more than just depression." [Shona]</p> <p>"We went off abroad .. and it started. She didn't know her way around and that and she used to be looking, you know, at the places and didn't know her way around and then I decided to take her to a neurologist" [Patrick]</p> <p>"We did go to the doctors, that's right, things were happening and she was getting us right irate. She was saying things, doing things and we were getting really ... and in the end, we said we couldn't stand it any longer because that's when we discovered that we both</p>

had blood pressure as well, high blood pressure." [Elsie & Brian & Brian]

"So this is in December 1993 and I called the doctor out. And I said to her well, she had got a sore mouth and I said to her, you're obviously run down, so I'll get the doctor out and while he was there I said to him we have really got a problem, I cannot cope with her tempers" [Ann]

"Anyway, in April 1994, the cat we had at the time had an accident and had to be out to sleep. Now, her reaction was as if nothing had happened. Now when our old cat died two years before that, she was hysterical, so we knew then that we had a real problem. We started ringing the doctor" [Ann]

"And in the end, I was feeding her and food was coming out the side of her mouth and she was choking on just a drink and I got the doctor out again and he said, "Oh I think we ought to get Dr X (consultant psychiatrist), so I said yes, well something is going wrong, because to my mind she was dying. I ended up making four phonecalls to the surgery, in the end Dr X came out and she had got haloperidol poisoning. I didn't realise with her legs, but when she did the reflex test, there was nothing, and what it was doing in fact was working on her throat muscles and paralysing them" [Ann]

"I don't know why, I have no idea why at all, but for some, unknown reason, he quite suddenly thought he had got cancer of the stomach or something. I had no idea why. And it was from that moment that we went to the GP eventually and said perhaps he could be checked out and it was that check-out in fact" [Evelyn]

"Well, my husband went through a period of losing things, not knowing where he had put things. He has always been absolutely meticulous about his paperwork. That is what he had done all his life, and things would be put in the wrong place and then after a while, he started getting very anxious about everything, money, worrying and all this. Lost a lot of weight. And that is when I decided that you know, suggested that he went to the doctor" [Moir]

"We were there for something else" [Wendy]

PRACTICAL SUPPORT:

Helpful:

Advice information and access:

"He's put me in the right direction" [Shona]

"He [consultant] said "I'll give you all the information. And he did. He gave me booklets of all the associations around, vol-care, age concern, all the booklets to read." [Shona]

"Well I suppose that the most helpful thing was having it confirmed that what we suspected was true. Knowing, as I say, what you're up against, you can then think [pause] you can focus on it can't you. You can go and read up on it, or if there is anything on the radio, I will listen to it and see what I glean from other peoples' experiences" [Ann]

"She [consultant] is the only person actually who took me on one side and said "Now this doesn't get any better. It can only get worse" sort of thing, and all the horrific things you can expect, and all that. And I said "Well I'm not bothered" so I said "What will be will be" and that's it you see, it doesn't truly bother me, erm she was the most in-depth." [Evelyn]

	<p>"She took me on one side and told me in detail what all how it would get worse" [Evelyn]</p> <p>"They [GP] got help with the day centre" [Wendy]</p> <p>"Well only that he prepared us for the fact that she would get worse, but that there was nothing that they could do, no treatment or anything" [Wendy]</p>
Timely service:	<p>"I mean she didn't leave no longer than about three months from when we went to her with depression." [Shona]</p> <p>"Then I went to the neurologist up there , he was pretty quick" [Patrick]</p>
Perceived competence:	<p>"And I've got confidence in that doctor" [Shona]</p> <p>"He was good" [Patrick]</p> <p>"He was good, he knew his job" [Patrick]</p> <p>"You see what people don't understand and I don't seem to find, perhaps doctors do, is the difference between anxiety and depression. Two quite separate things. And she [consultant] knew that and she whipped him off his anti-depressants and put him on melerill and he took, he was having one twice a day, he took that days' melerill and he was perfectly normal from that day onwards" [Evelyn]</p>
Unhelpful:	
Information and advice:	<p>"We haven't been given any information at all with regards the deterioration of the illness, only what I've read. I'm learning as I go along. No-one has sat down and said this is what is going to happen, you are going to see a deterioration over x number of years, or Eric will stay as he is. We've been told nothing about the deterioration of the illness, nothing at all." [Shona]</p> <p>"I haven't been told. All I was told was that Eric had got Alzheimer's disease, no-one has sat down and said to me, this is how the disease progresses. No-one has told me anything about the disease. I've learnt by reading, going to the library and the knowledge that I've had prior to that from working in a nursing home as a care worker. Other than that, no-one has told me anything about the disease at all" [Shona]</p> <p>"No-one from the medical profession has sat down and said this is what your husband is suffering with and this is how the disease will progress. Whether it be 1,2,5 years. This is what your husband will probably end up like. This is what he's going to get like, incontinent" [Shona]</p> <p>"Marvellous, can't fault it, really can't, but it's just that they haven't gone into detail of how the disease progresses at the moment. I'm just toying on the outside of it, so I'm just on the outside of it, I'm not really getting into the in-depth side of Alzheimer's disease" [Shona]</p> <p>"No, nobody says that. Nobody has ever sat down and told me that. Not that I suppose that you really wan to know. You might not want to know, some people want to know, others don't." [Patrick]</p> <p>"But no-body has ever said anything, the doctor" [Patrick]</p> <p>"The consequences of it and that, how long it takes and that, never came across" [Patrick]</p> <p>"Oh. I wasn't told. Dr x (consultant) didn't explain anything as</p>

	<p>such, she just said the brain is dying" [Ann] "I think if she could have sat down and explained what I was going to be up against" [Ann] "But it was not discussed with me. It was not discussed, what was actually going wrong and nobody has actually discussed what will happen in the end." [Ann] "I was never really told anything, by that I mean, I think I was sort of gently patted on the head and told well, he's got dementia. That was it, that was my full information" [Evelyn] "But I mean, I didn't get what I would call any information. Nobody told me anything excepting Dr x (consultant)" [Evelyn] But everyone has been charming, kind, helpful in every sense of the word but the actual "what it's all about department". Well, it's just that you have got it and that's your hard luck" [Evelyn] "No, well, we were not told very much, nothing really, no nothing" [Wendy] "I can't say that they were very forthcoming" [Wendy] "Well, I mean the only information really was the fact that she had got dementia" [Wendy]</p>
Access to services:	<p>"I think I had to struggle to get into the system" [Patrick] "I suppose you would say it was one of the things I think they let us down a bit. She never actually saw a specialist. He [GP] put us in touch with a specialist, 'cos he even knew his name, who was going to come and the next thing, it was a cpn who turned up. It's the only side you could say that they let us down." [Elsie & Brian & Brian] "I insisted that he was seen by her (consultant) but nobody would have ever suggested it I hadn't asked for it" [Evelyn]</p>
Perceived lack of competence:	<p>They sent me over to a psychiatrist who couldn't make head nor tail of her " [Patrick] "The doctors [GPs] they were a bit vague about it. Of course, now they just refer you up to the specialist" [Patrick] "He sent this report to the local GP who didn't come back to us, so I have no idea what was in the report" [Ann] "Nina's own GP came in after he got a report from Dr x (consultant) and he was embarrassed. I felt sorry for him because he sat there and he said "Well she could go on for a long time and, but really, I don't think she will", he just didn't know how to tell me" [Ann] "But I was given a sheet which turned out to be out of date information, all the 'phone numbers were wrong" [Ann]</p>
EMOTIONAL SUPPORT:	
Helpful:	
General, positive comments:	<p>"She was marvellous, our GP, absolutely marvellous." [Shona] "I can't fault my GP in any way." [Shona] "The consultant [psychiatrist of the elderly] has been wonderful." [Shona] "He [consultant] was really marvellous" [Shona] "He's [consultant] lovely, so lovely" [Shona] "I suppose they did their best really" [Patrick] "Well I think to fault it" [Patrick] "Our doctor is great" [Patrick] "The geriatrician ... a very nice man" [Evelyn] "Everybody was very charming and helpful and fell over backwards to be kind and pleasant" [Evelyn]</p>

	<p>"But everyone has been charming, kind and helpful" [Evelyn] "We changed over to the other member of the practice and it worked like a charm" [Moira] "Our doctor was wonderful" [Moira] "As far as we were concerned, I have got no grumbles" [Moira] "Our doctor was very good, very understanding" [Moira] "We had known our GP for 18 years and he knows us" [Moira] "The doctor we used to have was very nice, so that was okay" [Wendy]</p>
--	---

<p>Emotional Support:</p>	<p>"She was marvellous [GP] she gave us a lot of support, a lot of support" [Shona]</p> <p>"The consultant. He said "Eric has got Alzheimer's disease, but we will always be here. There's a back up team that will help you. You're not alone. Don't try and go it alone" he said" [Shona]</p> <p>"[He said] Use them [team], they are there for you. If you need a carer to come in and sit with Eric while you go out for a few hours, there are voluntary carers. Well use them, they are there for you, don't try and go it alone" [Shona]</p> <p>"Consultant gave me his secretary's number and said that if you need me at any time to talk, here's this number and you ring it and we are there for you. We are there for you when you need us" [Shona]</p> <p>"If we wanted more help, I dare say, you know, he would offer to get it for us" [Elsie & Brian and Brian]</p> <p>"Clive has a good relationship with the GP" [Moira]</p>
<p>Unhelpful:</p> <p>Emotional Support:</p>	<p>"I suppose they see it all the time, it's not such a big thing to them, what can I say" [Patrick]</p> <p>"I got the impression it was considered that Nina was at the stage that she should be put away and I got the impression that it was felt that I didn't need to know anymore because the body was going to be whisked away and it was no longer my responsibility" [Ann]</p> <p>"When Dr x came out she got the forms and said, I'm admitting her to hospital, and I said she's not leaving this place unless she's in a coffin" [Ann]</p> <p>She (consultant) said "You won't get any help" [Ann]</p> <p>"As I say, she was quite brusque with me when I said she was not going into a home" [Ann]</p>
<p>The way in which the news was given:</p>	<p>"I wished that they had taken their time and asked the family, had us together and said to my daughter and myself "your father has got or your husband has got Alzheimer's disease. Do you want him to be told? Or would you like us not to tell him and just let you cope with it on your own?" I think I would have liked some time to have thought about that, but it happened so quickly, I don't think they even thought about how it would effect us as a family and Eric knowing, I don't think we were given an opportunity to decide" [Shona]</p> <p>"it was told to me and Eric in the surgery when we went back to the consultant, he said that he's got Alzheimer's disease, but he didn't say it out loud "Oh, you're suffering from Alzheimer's disease", he just said "Your Eric has got Alzheimer's disease" Not making it a big issue at that time, but I do wish we had been given a chance to talk about it" [Shona]</p> <p>"Well I suppose it was that much of a shock and a worry to you, you don't know what you have been told really. I can't remember everything" [Patrick]</p> <p>"The way I was spoken to, reduced me to tears with anger, but if I was a weaker person I would have thought what the hell's going on. You know, being if I was an older person and that had been say my wife, or my husband who someone has just written off like that, I'd have been devastated" [Ann]</p> <p>"It would have been nice to have somebody sit down and discuss it,</p>

	perhaps not so much then, but if somebody came back a week later, saying now you have thought about it, are there any questions, do you still want to keep her at home? What kind of support do you need? Perhaps after you had got over the initial shock" [Ann]
--	---

CATEGORIES RELATED TO SHARING:

The influence of cognitive impairment on the decision to share information.	<p>"Because Eric is in a state now, you tell him something, it's gone. He can't store anymore. So I do feel that trying to explain to him now will be a waste of time. I think that the less he knows now, the better it is" [Shona]</p> <p>"I don't think she never, I don't think she knew." [Patrick]</p> <p>"No, well they discussed it with me when she was there, but I don't think even at that time...it seemed to come pretty quick on her" [Patrick]</p> <p>"No-one actually said because I don't think she could take it in" [Elsie & Brian]</p> <p>"It wouldn't mean a thing" [Elsie & Brian]</p> <p>"There was no way we could have told Nina. She would not have understood" [Ann]</p> <p>"It is all discussed. I know he won't remember it two seconds later." [Evelyn]</p> <p>"It is stupid saying to someone who can't fully understand" [Moirra]</p> <p>"I think because she had got to a stage where really it had progressed because we didn't know at the time that this was what was wrong. And by the time we got her to the doctor she was not able." [Wendy]</p> <p>"She would not have understood" [Wendy]</p>
--	--

Protectiveness:

Protecting the person from knowledge of their illness at all:	<p>"As it is now, yes, as it is now, I do feel I wished he had not been told because he is that bit younger, because if they'd have just said "You're suffering from depression", I'm wondering would he be coping better than he is now? Because I'm thinking he's beginning to look ill and drawn. Whether he's thinking to himself "How long have I got?" [Shona]</p> <p>"There was no way we could have told Nina. She would not have understood. Erm...and also again, if we, if she had known in the early stages, I don't think I would have told her. Going back to what happened to her brother, two brothers and sister [all had killed themselves on entering residential care]. I wouldn't have told her. Not...because she couldn't cope with it, she would have taken her own life. You have to be very careful. [Ann]</p>
--	--

Protection from the horrific details:	<p>"Eric did say to her [OT] yesterday about the disease. "How will I end up?" and she looked at me as if to say "Have I got your permission? How do you feel?" And obviously she was a little bit apprehensive and she did say to Eric "You could stay like you are for some time, let's live day by day and don't worry about tomorrow, let's live day by day, when we get to that bridge we will all cross it together, you won't be going alone". She was so helpful and he seemed relieved at that. I looked at his face and I thought "She has given him hope." We know there isn't, but she has given him...he's got to live day by day and not worry what next year is going to bring" [Shona]</p> <p>"I don't think maybe some people would like to know, really. What it is, is that they are going mad really, that's what it is. They call it dementia, the call it Alzheimer's disease, mad that's what it</p>
--	--

	<p>is in a way" [Patrick]</p> <p>"But it does depend on the person. I think it is up to the family to know whether or not that person can cope, because especially with dementia, you are looking at something you can give no hope for" [Ann]</p> <p>"She [doctor] took me on one side and told me in detail what all how it could get worse ... That was never said to him. I mean I don't say things to him that haven't happened. I mean I can't see much point really, can you?" [Evelyn]</p> <p>"I have the Alzheimer's Disease Society newsletter, but I don't show it to Clive, because there are things in it that I know he would worry about. Hearing about what might happen in the future. And I think we have just got to take it from day to day otherwise it is stupid saying to somebody who can't fully understand, well you might lose your memory altogether and not be able to recognise your wife" [Moira]</p>
Perceptions about the protectiveness of other people:	<p>"I don't think that they conceal anything, I think that they are more concerned about my well-being as a carer, being young, they feel, is it wise. Perhaps we'll leave Shona until it starts to progress and then we will go into that stage and gradually do it" [Shona]</p> <p>"They do worry about you, yes, I think they do. I think they are more concerned about my well-being at the moment that Eric's, because he is being cared for" [Shona]</p> <p>"you see, I had a bit of trouble myself, I had cancer at the time, I had an operation with cancer so I had a lot of pressure personally, you know" [Patrick]</p>
Protecting the person in other ways:	<p>"I have marked my plugs "Do not turn off" because one weekend he turned off my freezer and I lost quite a lot of food, but I didn't tell him, I thought no, I can't worry him, he has got enough to cope with" [Shona]</p> <p>"I have got to be honest, I love my husband dearly, but I hope that his span of life is not too long so that he goes to the extreme of Alzheimer's disease . I'm not being wicked, no way, but I would like to be happy for him so that he doesn't go into complete double incontinence, can't feed himself, can't hear, can't see, already his hearing is not 100 percent. I would hate him to go on too long. I'd like that his life would .. enjoy his life now while it's got quality, but when it gets that he's got no quality, I'd hope that his life would come to an end, but obviously we can't do that" [Shona]</p> <p>"Do you know, my daughter said "I would prefer it to have been a tumour on the brain, Mum, when he had a brain scan than have what he's got now, because she said we know if it was a tumour he would have gone peacefully. As it is, its a long drawn out ..." [Shona]</p>
Previous experiences of protecting people from bad news:	<p>"My mother knew what was wrong with her. She fought to the day she died. I had a friend who had stomach cancer at the age of 40. She knew what was wrong and she fought. Now, when my father was told he had lung cancer, the day they told him, he died, we brought him home from hospital and he wouldn't speak. He literally shut himself off and he was given six months to live and he died within eight weeks. And some people are like that, and some people can cope and can fight back" [Ann]</p>

Openness:	
Facing up to the illness:	<p>"He knows he has got Alzheimer's disease, well I tell him that's what I call it, dementia, Alzheimer's disease. anything you like to call it. I said what you have got is jolly bad luck. If it wasn't you it might be me." [Evelyn]</p> <p>"I spent quite a time, a few hours. We went shopping and what have you, and in the afternoon I said to him, "Come and sit down. I have got some rather bad news" and he said "Is it health -wise?" Because at this stage he was reasonably clear, it was just this forgetfulness and anxiety. And so I told him, and I don't think it really sunk in and we just went on from there." [Moir]</p> <p>"I knew that Clive would want to know. He would want to know you know in the same way I would like to know if I had anything terminal wrong with me. I would much rather face up to it and deal with it than to be in the dark and have people whispering and you know." [Moir]</p>
The importance of maintaining an open relationship:	<p>"Oh I discuss everything with him. Because I know that, you see, that whatever I say, everything goes on as normal as if he has no Alzheimer's disease at all." [Evelyn]</p> <p>"Well Clive and I have never had any secrets amongst each other. We have been married 49 years and we have always been completely honest with each other ." [Moir]</p> <p>"I couldn't in all honesty keep something to myself without sharing it and also I know that Clive would want to know" [Moir]</p> <p>"I wouldn't have dreamt of having a secret" [Moir]</p> <p>"I think that if you are a reasonably intelligent person, then you know what is going on, or that something is going on." [Moir]</p>
Openness about wider issues:	<p>"That's life isn't it. You have to be able to communicate with people about good things and bad things just the same" [Evelyn]</p> <p>"We talk among friends about dying because they have all got different things wrong with them, and I say Oh well, you know, if I don't shoot him before, and that kind of thing, so in that way we have a very open relationship" [Moir]</p> <p>"I mean, I like to know, I'm not one of these people that like, if something is wrong, it is wrong and to be told" [Wendy]</p>
Challenging stigma:	<p>"But I don't mind discussing all this, because it should be out in the open" [Evelyn]</p> <p>"It becomes acceptable" {if you talk about it} [Evelyn]</p>

Part Two: Summary of contact with medical services:

Participants were asked about their satisfaction with the contact with medical services such as GPs, Consultants and Community Psychiatric Nurses when they had consulted them and were given a diagnosis of dementia. These comments were divided into helpful and unhelpful:

Helpful	Unhelpful
Positive comments about overall service. Advice, information and access to services. Finding out what was wrong. Timely response. Emotional support. Perceived competence of professionals.	Lack of information and advice. Difficulty in accessing service. Perceived lack of competence. The way in which the information was shared.

Helpful contact with services:**Overall satisfaction:**

All the participants felt that the professionals they had contact with had been of some help. Those people who described the most positive experiences, commented on their overall friendly and pleasant approach:

"She was marvellous, our GP, absolutely marvellous"

"Everybody was very charming and helpful and fell over backwards to be kind and pleasant"

Practical advice, information and access to services:

Some positive comments were made in five interviews about the practical advice and information received about the diagnosis and the services available to help. For example:

"He [consultant] said I'll give you all the information and he did. He gave me booklets of all the associations around, volcare, age concern, all the booklets"

However, for three people, it was also helpful simply to be prepared for the future. This was summed up:

"He prepared us for the fact that she would get worse but that there was nothing that they could do, no treatment or anything"

"Well I suppose that the most helpful thing was having it confirmed that what we suspected was true. Knowing, as I say, what you're up against, you can then think [pause] you can focus on it can't you. You can go and read up on it, or if there is anything on the radio, I will listen to it and see what I glean from other peoples' experiences"

Timely response:

Two people felt that when they consulted a doctor to find out what was wrong, the services responded quickly:

"I mean she didn't leave no longer than about three months from when we went to her with depression."

"Then I went to the neurologist up there, he was pretty quick"

Emotional support:

For some people, the contact with doctors was seen as providing an emotionally supportive relationship. Three people commented on how much they valued reassurances given by the doctors that they could be contacted if new needs arose.

"Consultant gave me his secretary's number and said that if you need me at any time to talk, here's this number and you ring it and we are there for you. We are there for you when you need us"

"If we wanted more help, I dare say, you know, he would offer to get it for us"

Perceived competence of professionals:

Feeling that the professionals were competent and knew their job was valued by three people. One person said that she had "confidence in that doctor" and another said of the neurologist "He was good, he knew his job".

Unhelpful contact with services:

Information and advice:

The most comments were made about the lack of information given at the time of diagnosis. There was a sense that the carers were left feeling that they were "on the edge" of what they needed to know. Furthermore, they all reported having found out more from other sources. In particular, it was information about the future which seemed to be missing. This was summed up by three people:

"Marvellous, can't fault it, really can't but it's just that they haven't gone into detail of how the disease progresses at the moment. I'm just toying on the outside of it, so I'm just on the outside of it, I'm not really getting into the in-depth side of Alzheimer's disease"

"No, nobody says that. Nobody has ever sat down and told me that. Not that I suppose you really want to know. You might not want to know, some people want to know, others don't"

"I think if she could have sat down and explained what I was going to be up against"

Only one person felt she had been given enough information about prognosis, and this was from one consultant:

"But I mean, I didn't get what I would call any information. Nobody told me anything excepting DrX (consultant)."

Difficulty in accessing services:

In three interviews, people talked about how they had struggled to gain access to what they felt were appropriate services when they wanted to find out what was wrong. One man's wife was first seen by a psychiatrist who he found unhelpful, while another person had to ask specifically for her husband to be seen by a consultant. In another interview the family were told by the GP that they would be sent an appointment with a consultant, but this never arrived because he was too busy. One person described his experiences as:

"Struggling to get into the system".

Dissatisfaction with the way in which they were told about dementia:

Four people felt dissatisfied with the way in which they were told about dementia and the level of support they received at the consultation. One person felt she was not given an opportunity to decide what she wanted:

"I wished that they had taken their time and asked the family, had us together and said to my daughter and myself "Your father has got Alzheimer's disease. Do you want him to be told? Or would you like us not to tell him and just let you cope with it on your own? I think I would have liked some time to have thought about that, but it happened so quickly, I don't think they even thought about how it would affect us as a family and effect of my husband knowing. I don't think that we were given the opportunity to decide"

Two people felt there was no opportunity for them to ask questions after the initial shock had worn off and that information was given or services offered without adequate explanation:

"Well. I suppose that it's that much of a shock and a worry to you, you don't know what you were told really. I can't remember everything I've been told"

"It would have been nice to have somebody sit down and discuss it, perhaps not so much then, but if somebody came back say a week later, saying now you have thought about it, are there any questions, do you still want to keep her at home? What kind of support do you need? Perhaps after you have got over the initial shock."

One person felt that the consultant had been very "brusque" with her because she had decided to keep her relative at home, against her advice.

Perceived lack of competence:

Just as the carers valued the perceived competence of the professionals, they did not find it helpful when they felt them to be less than competent. For example by not sending reports, giving out-of-date information:

"They sent me over to a psychiatrist who couldn't make head nor tail of her"

"I was given a sheet which turned out to be out of date information, all the phone numbers were wrong"

1. Independent validity:

Feedback for people who took part in the research:

The feedback is divided into two parts. The first covers what you told me about your contact with services at the time you found out about dementia and any issues you raised about sharing information about the diagnosis of dementia with your husband. The second is a brief summary of the experiences of all the people interviewed about contact with services is included.

I am aware that you told me a great deal of other information about your experiences and that I have had to pull out the parts that were most useful to answer the research questions about experiences with professionals at the time you and your husband were given the diagnosis. I have changed all the names in the account and not named any services so that the information remains anonymous.

Part One: What you told me about your contact with services:

From your account it seems that you first noticed changes after your husband retired and for about a year you knew something was not right and even suspected that it was Alzheimer's disease. You said that at first you thought it was stress at work making him depressed, but that he was also losing abilities such as driving and holding conversations. The extent of the changes eventually became a problem, prompting a visit to the GP for help.

From your interview it seems that overall you are very happy with the contact you have had with both your GP and the consultant at the time of diagnosis. You commented that both were very supportive and helpful and that your GP responded quickly when you and your husband first approached her with concerns about depression. You said that the most helpful advice came from the consultant who told you "not to go it alone" and gave you a telephone number where you could contact the team if you needed to and gave you information about other services such as the Alzheimer's Disease Society.

You said that you were less happy with what you were told and the way that you were told. It seems that you have got most information about dementia from books, the Alzheimer's disease society and from other people, rather than from medical professionals. In particular, although you were told what was wrong, you were not given any information about how things might progress, which you said left you feeling as if you were on "the edge" of knowing about dementia, rather than having an in-depth understanding. When you were told, you said that you wished the doctors had given you more time to prepare. In particular, to have other members of your family present and to think through what would be best for your husband in the long-term. You wondered whether the doctors were protecting you for the time being in case you could not cope with more information.

Respondent validity:

Three people returned the feedback forms. Two people agreed that the summary was accurate and that the analysis was useful. They did not make any further comments. The third participant corrected one factual error and made some helpful comments which are produced verbatim:

"I think you should note that my doctor told me to "Get away - have a break on my own" I asked how? No answer. That is when I found [voluntary organisation] who have "made my day". I think such voluntary organisations need a mention. I'd be sunk without them. It seems the helpful and unhelpful equal each other out. I think much more stress should be put on talking about Alzheimer's disease. Make it common-place, don't hush it up. Those who'd prefer not to know need not listen, like cancer it must come out of the shadows. Mental illness is taboo. That is stupid when sex, AIDS, schizophrenia etc are on the TV daily. Why not Alzheimer's disease? Because it isn't "quite nice" to be thought mentally disturbed. This attitude must change. Carers need to be seen and heard at all times and in all places."

Research Diary:

Summer of 1995. On a visit to a voluntary centre providing day care to people with dementia, the organiser mentions how the words Alzheimer's disease in the title of the organisation could be a problem. She also says that sometimes she would turn over books if they had the words dementia or Alzheimer's disease displayed too prominently. She said that she didn't want to worry people or let them think that they had dementia, even when they did. This seemed a situation fraught with problems. What if the person saw it anyway? What difference would it make to them? Why don't people like talking about dementia?

January 15th 1996:

Struggling to sort out some practicalities and reading up on qualitative research. I have spoken to various people about the research, all of whom were enthusiastic and agree that sharing information is an issue for people with dementia and especially carers. One voluntary worker described how much easier she found it to work with a couple where the husband had been told. First ethics committee have given approval.

February 1st 1996

First meeting with a voluntary day centre through a very helpful CPN. The centre is very busy and welcoming. I am handed a plate of suet pudding as I come through the door. Spent a bit of time explaining the research to her. She calls over two women who she thinks might want to talk to me. Immediate dilemma as one is no longer caring for her husband because he died last year. However, they both want to talk and the whole business of sharing and communication is very alive for them. One woman is almost on the edge of tears describing how out of control the situation feels. Both want to help other people in any way they can through research, and I got the feeling that research was a way of doing something, or being in control of something. Arrange an interview with one.

22nd February 1996

First interview. Has to be done in the minibus, parked outside because the organisation have so little space.

23rd February 1996

Attend an evening carers group where I recruit more carers for the pilot. SO far so good, but no-one with dementia has been put forward yet. All the people I have contacted think that they probably only come in to contact with people when they need a great deal of care.

27th February 1996

Telephone call from another voluntary sector organisation who think they can help with carers and people with dementia. Unfortunately I have yet to get ethical approval to start in that area, However, I'm encouraged that there are some people out there with dementia who might want to participate.

19th March 1996

Go to do an interview with a carer who doesn't turn up. Ring her to find that her husband has died.

1st April 1996

Visit a woman who doesn't fit the inclusion criteria as her husband is in a nursing home. I spend some time talking to her about how she could get support through the organisation that I recruited her through.

8th April 1996

At last! Conditional approval from the second ethics committee. They want me to ensure that all the people with dementia that I recruit know their diagnosis by first getting the carer to sign a form and then getting a health professional to also agree that the person is aware of their diagnosis. This leaves me slightly uneasy. On the one hand I can see how important it is to safe-guard the people who don't know. It also feels like it undermines any autonomy the person has left.

10th April 1996

Analysed the first carer interview. It seems to make sense, which reduces my anxiety about the qualitative part of the analysis. I just need more people to interview. Surveys are gradually coming in, with a fair number of people agreeing to participate further.

6th May 1996

Now I am really starting to worry. All of my efforts to get people with dementia are coming to nothing. The only good thing is that surveys are now coming in and I decide to interview more carers just in case I have to abandon the part with people who have dementia. In supervision we talk about the possibility of a third ethics committee.

8th May 1996

CPN team very helpful for access to a group of carers who take surveys. In another conversation with the same team it becomes apparent that even some carers might not get to know the diagnosis either, especially if they are older themselves. Beginning to wish that I had not used the word "dementia", because everybody else is talking about "memory problems", but wasn't that the whole point of this research?

20th May 1996

Have a very interesting conversation with a psychiatrist for the elderly that I used to work with. She admits very candidly how difficult she finds the whole issue of sharing information and how she finds herself using euphemisms even when she tries not to. I reflect on my own practice when feeding back the results of cognitive assessments, is this a similar situation?

May 21st 1996

Enough carers have come forwards for interviews. The manager of the voluntary organisation who think they have got people with dementia who want to talk to me can't understand why all the "red tape" from the ethics committees. I have to stick

to it very carefully. She is worried that it takes away any power her clients had and that at least one person has a carer who would not let them participate, when she feels he would like to.

28th May 1996

Looks like I will go for a third ethical approval after all. Carers interviews almost finished.

3rd June 1996

Visit another carers support group at a day hospital. The charge nurse is very scathing about the whole study "Of course there is no point telling people, you only hurt them and then they forget and then you end up going round in circles". I tentatively suggest that it was hard if the person was asking questions themselves and she said "but you tell them it is memory problems".

6th June 1996

Provisional approval from the committee so I begin to make some initial telephone contact with services. It all feels a bit late. One service sounds brilliant, I wish I had heard of them before.

7th June 1996

No go on the service that sounded brilliant. They don't use the words dementia or Alzheimer's disease, people who are assessed by the service only get told that they have "memory problems".

10th June 1996

Much more luck with a CPN team. They think there may be two people. The carer interviews are analysed. I start to feel very uncomfortable about the feedback. It seems that the decisions about sharing were made on the basis of a very personal value system. It feels uncomfortable to feedback the account of all the interviews which includes people who made very different decisions. I don't want people to feel judged or that they have made the wrong decision because it is different. Decide to play safe and not feed it all back. Wonder if I am getting caught up in the protectiveness surrounding the area.

11th June 1996

I get told the joke I have used at the beginning of the introduction. It seems to sum some of what I have been hearing up.

12th June 1996

Finally! Two people with dementia who want to talk to me. I meet the first participant with his wife at home twice to fill in all the forms. I learn that he is in a drug trial as well. Research seems to be a way of coping with the dementia.

5th July 1996

Last interview. As I begin to talk to Jean, I seriously doubt that she has understood the consent procedure or remembers what she has. I check them out again. I proceed cautiously and decide not to get the tape recorder out. Then she

is suddenly very coherent and clear that she has Alzheimer's disease, but by the time it is too late to get the tape recorder out and I make notes as I go.

6th July 1996

Spend all my time rushing to get these last interviews analysed. I wish I had got more people. The project feels much more complete with the experiences of the people with dementia, although I feel I was floundering in the interviews for the right questions to ask. This would be easier if there was more time to build up a relationship with people because the issues they talk about are so deep. I'm left with the comments of people like Jean "I might as well be dead" and Shona "I wish it was cancer".