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**PERSONAL EXPERIENCES IN THE EARLY TO MODERATE
STAGES OF ALZHEIMER'S DISEASE:
AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS**

TANYA ELISABETH COALEY

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**Thesis Submitted In Partial Fulfilment Of The Requirement Of The
Degree Of Doctorate In Clinical Psychology (D.Clin.Psy)**

September 2001



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General Appendices – Section 5:

Copy of ethics approval letter from the School of Psychology

Copy of ethical approval letter from the North Wales Health Authority

Readers may consult the original thesis if they wish to see this material.

SUMMARY

Previous research has focused on measuring awareness in dementia with few attempts to define or clarify this concept, nor explore its meaning to the individual. The present study is preceded by a review of the concepts of insight and awareness, and the different approaches to understanding these drawn from the psychological, neurological and psychiatric literatures. The strengths and limitations of the different models are discussed and the case for further research in this area is presented. This is followed by a research study that explores the experiences of seven people in the early to moderate stages of dementia. Interpretative phenomenological analysis illuminates some of the psychological factors that contribute to awareness and how these factors impact upon self-concept. It is suggested that clinicians and services need to pay greater attention to the phenomenological experiences of individuals with dementia. Four superordinate themes emerged which were labelled

1. Relationship with memory
2. Relationship with professionals
3. Emotional experience of memory loss
4. Coping and maximising resources.

Each category compares and contrasts individual experiences and suggests that insight may be a complex concept that would be better understood by taking into account the psychological processes that contribute to individual awareness, and their subsequent impact on self-concept.

The research paper is followed by a critical review that outlines the strengths and weaknesses of this study, as well as the process issues that arose during the course of the research and the clinical implications.

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I am grateful to all the clinicians who have supervised me throughout the course, in particular Rudi Coetzer, the aforementioned Bob, Dr Neil Cheshire, Dr Caroline Eayrs, Dr Sue Wilcock, Karen Loane and Dr Mike Jackson. I would also like to thank Sharon and the rest of the Course Team for helping me to survive a very challenging but enjoyable Three years.

I would like to thank my cohort, alias my friends, for all the fun and the holidays together. I will never forget paddling in the sea at night, camping in gale force winds or the numerous picnics!

Gratitude also to my family - Jay and Rhys who have had to move to another part of the country for me and put up with all the ups and downs! Thank you to my Dad for reading a draft of my thesis, and my Mum and Nan for listening to all the moaning! I would particularly like to mention my Grandfather, William Elwyn Lewis, who's main goal was to see me complete the course and encouraged me to come to North Wales in the first place. While he died suddenly at the end of my first year, he has always been a tremendous inspiration to me and has given me the inner strength to keep going.

SECTION 1. ETHICS PROPOSAL

APPENDIX 1

APPENDIX 1

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RESEARCH PROTOCOL

A. Title

A Qualitative Investigation Of Insight In Dementia.

B. Principal Investigator

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C. Background to the research

In recent years there has been an increased interest in the concept of insight in dementia. This has generated considerable controversy with regard to a definition (Mullen et al., 1996). Numerous different definitions have emerged but in the context of this study it is defined as the ability to understand one's own problems or 'self-knowledge' (Markova & Berrios, 1995). Allan and Killick (1998) define insight as "an awareness of the presence and characteristics of the commonly agreed features of dementia" (e.g. memory, reasoning or comprehension difficulties etc.). For the purpose of this study - insight may also be defined as the person with dementia's understanding of the reason for their visit to the memory

clinic, any functional difficulties, their perception and understanding of the disease, as well as impact on relationships and life quality.

This study aims to explore multiple perspectives on insight (*person with dementia, carer & professional*) in order to gain a better understanding of the meaning of insight. Few attempts have been made to analyse the meaning of insight nor consider the implications for the individual in terms of quality of life, information, prognosis, management and consent. Preliminary research in this area suggests that insight is an important issue that has implications for service provision (SSRP, 1999). Individuals appear to differ in the intensity of their awareness of what is happening to them in dementia, and in the defence and coping mechanisms used. Greater understanding of how insight relates to mood, self-esteem, personhood, coping strategies, as well as relationships with carers, may provide some suggestions for strategies to help people with dementia address the personal meaning of illness, and to help them, where appropriate, to come to terms with their losses.

Few studies have explored insight in dementia in any depth. The studies that have been undertaken have mainly focused on insight in relation to aetiology or severity of dementia (McDaniel et al., 1991; Verhey et al., 1993). Taken at face value these studies suggest that cognitive failure leads to loss of insight (e.g. Mangone et al., 1991). Zanetti et al. (1999) highlights a tri-linear model of the association between insight and cognitive status, this estimates when the decline of insight begins and ends.

It has also been argued that unawareness of cognitive deficit may be disease specific (Wagner et al., 1997). While other studies have failed to demonstrate an association between aetiology and insight (e.g. Verhey et al., 1995).

Research on the relationship between insight and depression is conflicting. Several studies have provided some evidence that depressed mood co-occurs with preserved insight in Alzheimer's disease (e.g. O'Conner et al., 1990). Other studies have failed to find a statistically positive correlation between these two variables but have suggested a trend in the same direction (e.g. Feher et al., 1992). However, several studies that have failed to

demonstrate a relationship between insight and depression (e.g. De Bettignies et al., 1990). Reed, Jagust and Coulter (1993) found that subjects who were aware of their memory loss were no more likely to be depressed than those who had no insight.

Verhey et al. (1993) suggest that level of awareness of cognitive deterioration may be significantly related to the severity of dementia but not to depression or the score on the Hamilton Rating Scale for Depression. In this study the score on the item “psychic anxiety” showed a weak but significant correlation with the level of awareness of one’s deficits. These authors conclude that intact awareness of deterioration is not clearly related to the development of depression or depressive symptoms.

Several personal accounts of the experience of dementia have been published by people diagnosed in the early stages of the illness (e.g. McGowin, 1993; Goldsmith, 1996) and it has been argued that insight can be identified and explored by listening carefully to what people with dementia say in an interview or group session (Keady, Nolan & Gilliard, 1995). There is also some evidence that people in the more advanced stages of dementia may be capable of insight, but loss of language acts as a barrier to communication (Killick, 1994).

As indicated, the present study is based on the findings of a pilot qualitative study that explored the person with dementia’s experience of receiving a diagnosis (SSRP, 1999). This found that people with dementia are often able to talk with clarity and insight into their illness and that this is often overlooked by professionals seeking to provide services. Therefore, greater understanding of the variables that relate to insight may lead to new ways of supporting people with dementia and their families.

Increased understanding of insight is also important because the need for care as perceived by relatives and referring agencies often appears to be related, inversely, to the person with dementia’s awareness of their condition and disabilities (Mullen et al., 1996). However, there is some evidence that where appropriate opportunities have been made available, people with dementia are able to undertake useful psychological work on issues relating to their illness and other life circumstances (Husband, 1999). Increased understanding,

therefore, may enable people with dementia to benefit from psychological therapies (Bender & Cheston, 1997) and enable more specific targeting of interventions.

Insight is also implicit in questions of consent and responsibility. Where a patient with dementia is unaware of her/his cognitive difficulties, informed consent becomes difficult to obtain. Therefore, from a professional point of view, an understanding of how insight is affected in dementia may be very important and of direct clinical relevance.

Loss of insight may have a protective function in dementia (Markova & Berrios, 1995). These authors suggest that loss of insight may provide a helpful protection in the more severe stages of dementia. In the early stages insight may be more valuable and hence early loss presents a major problem for the individual and their carer.

No structured evaluation schedules of insight have been developed for use with people with dementia, and research into insight in psychosis demonstrates that where instruments have been devised, principal component analysis provides a single-factor solution, i.e. it makes more sense to simply ask people about the nature of their difficulties (Startup, 1997). Therefore, as insight is a complex concept that is difficult to measure quantitatively, for the purpose of gaining a more in-depth understanding, qualitative methodology is more appropriate.

D. Aims Of Research

To generate a series of subjective accounts of people with dementia's experiences following diagnosis, more specifically:

1. To understand the process of receiving a diagnosis for the person with dementia.
2. To understand the commonalities and differences between people with dementia's awareness and understanding of their illness.
3. To explore and gain some understanding of how awareness relates to the person with dementia's mood and quality of life, and to explore whether there are different levels of awareness.

4. To understand how a person's insight into their illness may impact upon their relationship with their carer, as well as the relationship between insight, carer stress, mood and quality of life.

E. Methodology

(i). Participants

Eight participants will be identified from referrals to the Memory Clinic and the Day Hospital. These participants will have received an assessment from the psychiatrist, psychologist, or the multidisciplinary team (the aim will be to recruit people in the early stages of the illness who are able to provide consent and talk about their experiences). Following discharge, participants will be approached by the trainee clinical psychologist and asked if they would be interested in participating in a study to gain some understanding of their experiences. If verbal agreement is obtained the participant will be sent the information and consent sheet on the study to read (* *see enclosed*). A week after this has been sent the potential participant will be contacted by telephone and if they remain interested in participating an introductory visit will be arranged to explain the procedure, assure confidentiality, and clarify any questions. If the participant is happy to participate (and their main carer is satisfied) they will be asked to sign the consent form. A copy of this form will be retained by the participant. A letter will also be sent to inform the GP and psychiatrist of their involvement in the study.

(ii). Procedure

Participants will be interviewed on their own at home, using a semi-structured interview schedule (* *see sheet enclosed*). Interviews will be taped for verbatim transcription. The initial interview will last for around 1-1.5 hours. Following the initial interview the data will be transcribed and a pre-liminary thematic analysis will be undertaken. The results of this analysis will be presented to the participant on a second visit in order to ensure that the themes reliably reflect their views. This has been suggested as a method of assessing validity in qualitative research (Henwood & Pidgeon, 1996).

Time scale:

Start date - October 2000

Recruitment - October to December 2000

Interviews - November to January 2001

Transcription - January to February 2001

Write up - February to start April 2001

Draft - By May 2001

Deadline - July 2001

(iii). Data Analysis

On completion of the data collection, qualitative methodology will be employed to analyse the data. The data will be inputted into the Nudist data analysis software package and the method of qualitative analysis to be employed will be Interpretative Phenomenological Analysis (IPA; Smith, 1996). This methodology will be employed because it is a qualitative method for understanding participants' perspectives. Researchers (e.g. Smith, 1996) suggest that gaining an 'insider view' is only possible through use of interpretative analytic work. This method is concerned with the individual's perceptions of events, rather than objectifying events, and it aims to explore participant experiences. It also explores how people experiencing the same illness might talk differently about it, thus illuminating the subjective perceptual process that are used to make sense of illness.

All data will be coded to ensure that no names are disclosed. Following transcription all recorded data will be destroyed.

A sample of the verbatim transcripts will be given to the supervisor and another trainee clinical psychologist to independently discuss and agree on theme categories. This will verify that the analysis is systematically achieved and supported in the data.

F. Ethical Issues

See ethics form

G. References

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Multiple Perspectives On Insight In Dementia

Semi-structured Interview Schedule (Participant/Carers)

**** Introduction & Rapport Building***

Confidentiality and consent will be re-emphasised and the information sheet will be re-read and discussed. Any questions will be addressed.

PARTICIPANT INTERVIEW

Some sample questions:

1. Open-ended questions about the person with dementia's experience of coming to the Day Hospital/Memory Clinic

E.g. "Tell me about coming to the day hospital/memory clinic"

2. Circumstances that led them to be referred for an EMI assessment

3. What they were told about their...(memory problem)

4. What this means to them and what they have understood about the nature of their difficulties

E.g. "What does... mean to you?"

E.g. "Did you know anything about... before coming to the hospital? If so, what?"

5. What could be improved about disclosure

6. What impact (if any) has this had upon their lives

E.g. "In what way has your life changed?"

7. What impact do they think their difficulties will have upon their lives in the future

8. Impact on mood and quality of life

E.g. "How does having (difficulty with memory) make you feel?"

9. Impact on their main carer

E.g. "Do you think your (memory difficulties) have affected your (carer) in any way? If so, how?"

10. Relationships with others

E.g. "Do you think the nature of your relationship has changed? If so, how? and when did the change occur?"

"Do you think people treat you differently now? If so, how?"

"How does that make you feel?"

(Headed Paper)

Information Sheet (1)

Date.....

RESEARCH STUDY - MEMORY

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Purpose of the study:

We are inviting people like yourself who have recently been seen at the hospital in relation to difficulty with memory to take part in a research project. The aim is to explore your thoughts and feelings about life. As part of this work we will be asking you some questions about your experiences and thoughts about your memory difficulties, as well as asking about how you feel and whether your quality of life has changed.

* To help the psychologist remember the information your answers will be taped.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any

time and without giving a reason. This will not affect any services you receive.

What will happen to me if I take part?

The psychologist will visit twice. The first visit is when the questions will be asked and taped. On the second visit the psychologist will check whether the information collected from the first visit represents your views or if you would like to add or change any of the information.

Will my taking part in this study be kept confidential?

All information which is collated during the course of the research will be kept strictly confidential. Any information about your views will have your name and address removed so that you cannot be recognised from it. The tapes will be treated as confidential and as soon as the research is complete they will be destroyed.

Thank you for considering to take part in this study

If you have any concerns, questions or comments about the research procedure or any other aspect of the study, you can contact myself -

Tanya Coaley
Trainee Clinical Psychologist
Heulwen Day Hospital
Ysbyty Gwynedd
Penrhosgarnedd
Gwynedd
Tel: 01248 385025

or Professor Bob Woods
DSDC, Neuadd Ardudwy
University of Wales Bangor
Normal Site
Holyhead Road, Bangor
LL57 2PX
Tel: 01248 382463

Any complaints about any part of this study should be addressed to either:

Professor C.F. Lowe

or

Mr. K. Thomson

Head of School of Psychology

Chief Executive

University of Wales, BANGOR

Ysbyty Gwynedd, BANGOR,

LL57 2DG

LL57 2PW

(Headed Paper)

PRIVATE & CONFIDENTIAL

Date:

To: General Practitioner / Psychiatrist

Dear

Re:

I am writing to inform you that Mr/Mrs..... has provided his/her consent to participate in a research study. This study will be submitted as part of my doctorate in Clinical Psychology at the University of North Wales, Bangor.

This study is a qualitative investigation into awareness of cognitive impairment, mood and quality of life in dementia. Your patient will be asked some questions about their awareness of the difficulties they have been experiencing, and their thoughts and feelings on these issues. Questions will also be asked to your patient's main carer and these will include their perception of the person's insight, mood and quality of life.

Ethical approval for this research has been obtained. If you have any concerns or require any further information please do not hesitate to contact me at the Heulwen Unit, Ysbyty Gwynedd (Tel: 01248-385025).

Yours sincerely

Tanya Coaley
Trainee Clinical Psychologist

Under the supervision of Professor Bob Woods, Professor of Clinical Psychology of Older Adults (01248-382463)



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CONSENT FORM

Research Study on Memory

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Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my care being affected.

3. I agree to take part in the above study

Name of Subject

Date

Signature

Name of person taking consent
(if different from researcher) Date

Signature

SECTION 2. LITERATURE REVIEW

To be submitted to: Aging & Mental Health

A REVIEW: INSIGHT AND DEMENTIA

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A review: Insight and dementia

Abstract

In recent years there has been increased interest in the concept of insight in dementia. This has generated controversy regarding a definition, as well as methodological problems when attempting to measure this phenomenon. This paper reviews this complex concept and different approaches to understanding insight drawn from the psychological, neurological and psychiatric literatures. The strengths and limitations of the different approaches and models are discussed. The case for further research in this area is presented.

A Review: Insight and dementia

Searching for a definition

The term “insight” has been the focus of a growth of interest in recent years aimed at the relevance of this concept to mental health. Despite growing recognition of its importance in clinical practice, the general literature is limited and confusing. In terms of dementia research, the person’s subjective experience of illness also remains a largely neglected area (Bahro *et al.*, 1995), and while people may be classified as falling into one of three groups: those having no insight, good insight or partial insight, there is little understanding of what this concept means (Markova & Berrios, 1992).

The Oxford Modern English Dictionary defines the term “insight” as - the capacity for understanding hidden truths, especially of character or situations - in psychiatry the term is used to refer to a state of mind or mental act, and knowledge of insight is inferred from the way a client behaves and responds to their illness (Markova & Berrios, 1992). Foley (1992: pp. 37) defined insight as “the capacity to discern the true nature of the situation, or as applied to dementia, the recognition of the fact, degree and implications of one’s own illness.” The concept of anosognosia has also been used in the neuroscience literature to refer to an individual’s lack of knowledge of a condition, usually motor (McGlynn & Schacter, 1989). This term was originally coined by Babinski in the early 1900s and was used to describe loss of awareness of hemiplegia. It subsequently evolved to cover general

unawareness of impairment associated with many different physical and cognitive deficits (Giacino & Cicerone, 1998).

Clinical descriptions of dementia report that unawareness of deficits or loss of insight is a major feature of the illness, and part of general cognitive deterioration (Schneck *et al.*, 1982). People with dementia are said to become increasingly unaware of their symptoms as their illness progresses, for example explaining poor performance on memory assessments being a consequence of age or poor concentration (Feher *et al.*, 1991). Early systematic investigations also suggest that insight may be disease specific, and as a result people with Alzheimer's disease are perceived to be less insightful into their general condition than those with multi-infarct dementia or Parkinson's disease (Danielczyk, 1983).

In the majority of studies, the terms insight or awareness have been used interchangeably, as well as those of anosognosia and unawareness. However, despite observation of lack of insight in clinical descriptions, there remains a lack of experimental evidence concerning this phenomenon, and there is little understanding about the nature of insight in relation to different people and different disorders, and the factors that may be influencing it.

Markova and Berrios (1992) suggest that the meaning of insight in clinical practice is more complex than simply the knowledge that clients may have about their self and illness, as is generally assessed in psychiatric interview. Insight may represent a form of self-knowledge that includes not only information of a person's difficulties and personality traits as applied to the self, but also an understanding of the way in which the self interacts with the

environment. But many questions in this area remain unanswered, and there is little understanding of why some people have a better understanding of what is happening to them.

Insight, denial and mood

Some studies use the term 'denial' to represent lack of awareness of memory deficits or ability to undertake activities of daily living (Sevush & Leve, 1993). Conceptual issues also arise with regard to the meaning of denial, i.e. to what extent is the information that has been lost beyond a person's consciousness. This term is often used in a psychodynamic sense to describe states where information has been 'repressed' or 'suppressed'. Denial of cognitive difficulties has been suggested as a defence mechanism for lack of insight, and denial has been reported in illnesses such as cancer and myocardial infarction (Snyder & Higgins, 1988). In these cases, denial appears to primarily occur in the acute stages of illness and may serve an adaptive purpose by enabling patients to activate psychological resources.

Weinstein *et al.* (1994) attempted to correlate denial with severity, duration of illness and age of onset. These authors conclude that denial and insight may represent different concepts as denial failed to correlate with severity of cognitive deterioration.

Blass and Barclay (1985) suggest that as clients with Alzheimer's disease deteriorate and lose insight their mood appears to improve. They propose that the presence or absence of insight may have important diagnostic implications as denial may represent a protective

mechanism against depression. However, subsequent research criticises these observations as lacking empirical validation (Feher *et al.*, 1991).

Early studies suggest that as insight may be lost at a relatively early stage in Alzheimer's disease, clients with this type of dementia are less likely to be depressed (Jenike, 1986). The research literature also cites numerous studies which suggest that depressed mood co-occurs with preserved insight in dementia (e.g. O'Connor *et al.*, 1990; Sevush & Leve, 1993).

Similarly, a trend in the same direction has been indicated in studies where there is a weak but non-significant relation of depression to insight (e.g. Feher *et al.*, 1992). Mullen *et al.* (1996) refer to the need to interpret these studies with caution as under-rating of memory performance may also be representative of depressed people without dementia in general.

The study by Feher *et al.* (1992) has been criticised for failing to describe how the data was collected, for example whether information was obtained from the client, carer or both (Ott *et al.*, 1996).

Verhey *et al.* (1993) examined 170 people with dementia to investigate whether depressive symptoms were more likely to occur in patients with some degree of awareness of cognitive deterioration. Awareness was rated on a 4-point scale according to the discrepancy between the patient's and carer's reports. The results suggest that the level of awareness was positively related to the severity of dementia, and failed to correlate with depression. It was also found that the score on the item "psychic anxiety" had a weak but significant positive correlation with insight. These researchers conclude that insight into cognitive deterioration may not be clearly related to the development of depression or depressive symptoms.

Suicide

A study by Rohde *et al.* (1995) presents two case studies of insightful, highly educated people with dementia who committed suicide. Reporting of such cases appears to be rare and there is scant evidence that clients with insight in the early stages of dementia attempt to commit suicide.

Insight and aetiology

Some studies suggest that, independent of dementia severity, lack of insight of cognitive difficulties may be disease specific (Wagner *et al.*, 1997). These researchers suggest that people with Alzheimer's disease are significantly more likely to lack insight when compared to people diagnosed with vascular aetiology. Initially there appears to be some support for this hypothesis, but empirical evidence is lacking and many methodological weaknesses have been highlighted, for example, these studies mainly involve in-patients on specialised wards in the later stages of dementia. Patients with co-morbid depression were also more likely to be diagnosed as having vascular dementia, and the studies fail to take into account confounding factors such as age and sex. Verhey *et al.* (1995) criticise aetiological studies on the grounds of lack of clear diagnostic criteria, and the vague operationalization of terms. A subsequent study by Verhey *et al.* (1995) involving 48 patients with Alzheimer's disease and 48 with vascular dementia failed to demonstrate that insight, depression and personality distinguished patients with different types of dementia. These findings also appear to be consistent with research by Cummings *et al.* (1995) and Ott *et al.* (1996).

Insight and severity of dementia

A study by Reisberg *et al.* (1985) assessed awareness of cognitive deficits by comparing a control group, 5 subjects with “senescent forgetfulness”, and 25 subjects diagnosed with Alzheimer’s disease. Subjects were interviewed and questioned about their own functioning and their spouses’ functioning, and spouses were interviewed. The results suggest that subjects with senescent forgetfulness rated their memory problems as worse than the control group, the group with early dementia rated their functioning as worse than those with senescent forgetfulness, while the subjects in the later stages of dementia rated their memory difficulties as progressively less severe. Consistent with these results, Anderson and Tranel (1989) found a positive correlation between unawareness of deficits and degree of intellectual deterioration (as assessed by a standardised interview). While other studies (e.g. Feher *et al.*, 1991) have criticised the study by Reisberg *et al.* on methodological grounds for failing to take into account individual variation in self-awareness, i.e. subjects who had insight despite significant cognitive impairment versus subjects who denied symptoms despite mild cognitive impairment.

Subsequent research suggests that poor insight may have a linear correlation with severity of dementia (Lopez *et al.*, 1994; Mangone *et al.*, 1991; & Ott *et al.*, 1996). However, there are conflicting findings in this area for example, McDaniel *et al.* (1995) rating insight using unstructured and structured interviews found that after two years 33% of people with Alzheimer’s disease demonstrated a decline in insight and 10% improved, i.e. level of insight was unchanged for the majority.

Zanetti *et al.* (1999) report that the relationship between lack of insight and cognitive functioning may follow a non-linear pattern, and they suggest that scores on the Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975) may be identified between preserved, moderately impaired and absent insight. This study subscribes to a trilinear model, whereby the association between insight and cognition follows three periods: an initial period of stability prior to detecting decline, a period of decline, and a final period where severe insight impairment reaches a plateau. They suggest that identifying these periods may have implications for improving care planning.

Explanatory mechanisms for insight

It may be important to qualify definitions of insight in terms of underlying mechanisms in order to improve understanding of this controversial phenomenon. Research aimed at defining the causative mechanisms of insight have ranged from biological and neuropathological explanations to psychodynamic interpretation.

Neurological and biological approaches to insight

The neuroscience literature refers to awareness on several different levels (McGlynn & Schacter, 1989). Unawareness can range from *global disturbance of consciousness*, such as being in a persistent vegetative state; *domain-specific unawareness*, for example in hemiplegia or hemianopia; *executive unawareness*, relating to difficulties with judgement, planning or initiating goal-directed behaviour; and *disordered self-awareness*, for example being unable to evaluate beliefs while taking into account implications and consequences.

A number of neuropsychological studies have attempted to identify the neural mechanism associated with lack of insight, for example Mangone *et al.* (1991); Michon *et al.* (1994); Reed *et al.* (1993); and Ott *et al.* (1996) have suggested that lack of insight in Alzheimer's disease may be associated with frontal and right hemisphere impairment.

Several models have been proposed to account for the manifestations of anosognosia. Schacter's DICE model (McGlynn & Schacter, 1989) proposes that there is a brain module, termed the "conscious awareness system" (CAS). The neural basis of this system is suggested to be the parietal lobes and output connects to an executive system, namely the frontal lobes. Anosognosia syndromes were suggested to be either general or specific, whereby a general anosognosic syndrome occurs following damage to the CAS or frontal executive system. The general anosognosic syndrome is separated into: damage to the frontal lobes leading to lack of awareness of complex deficits (for example, cognitive impairment), and lack of awareness of perceptual or motor deficits related to damage to the parietal lobes. In contrast, a specific anosognosic syndrome occurs as the result of disconnection of a specific sensory system from the CAS. Therefore, according to this model varying manifestations of unawareness occur when the CAS is damaged or 'cut off' from other brain modules.

Agnew and Morris (1998) expand this model in relation to Alzheimer's disease. They identify three types of unawareness in Alzheimer's disease. Firstly, *primary* relates to unawareness of inability to function across all areas of cognition, and this results directly

from damage to the CAS; *mnemonic* is the second type, whereby the person believes memory to be functioning normally, owing to failure to update semantic memory; and *executive unawareness* refers to perception of memory errors without being able to register the implications of errors.

Ott *et al.* (1996) suggest that right hemisphere and frontal dysfunction may contribute to loss in Alzheimer's disease, and that is consistent with psychometric tests of executive and visuospatial abilities. A further study, also by Ott *et al.* (1996), suggests that unlike impaired awareness of memory deficit, impaired awareness of activities of daily living does not correlate with tests of memory. In this study reduced awareness for ADL was correlated with Trails A and mazes, tests based on concentration, sequencing, and visuospatial ability. Mangone *et al.* (1991) also suggest that impaired awareness of ADL deficits may relate to continuous performance on visual reproduction tests. Nevertheless, studies into the relation between insight and the localisation of neuropsychological measures have been criticised on methodological grounds, for example, Mullen *et al.* (1996) report that the results of these studies are often based upon controversial psychometric assessments that are supposed to reflect localisation of function.

Psychiatric approaches to insight

The psychiatric literature on insight focuses mainly on psychosis, and here it is suggested that the concept represents an amalgam of three constructs: the ability to identify certain mental events as pathological, the individual's ability to recognise that they have a mental illness, as well as compliance with treatment (David, 1990). These models can be criticised

for requiring the person with psychosis to agree with the psychiatrist and to be able to acknowledge 'normal' social judgements (Harper, 1992). Clare (2001) suggests that these models relegate the person with psychosis to the role of passive recipient of psychiatric treatment, whereas studies that take a phenomenological approach (e.g. Greenfield *et al.*, 1989), present the person as actively seeking to find meaning in personal experience and to cope with difficulties.

As indicated previously, more recently, psychiatrists such as Markova and Berrios (1992) acknowledge that awareness may be socially constructed and open to interpretation by the psychiatrist. They suggest that a person's level of insight may depend upon the individual's interpretation of information, as retained from their internal world (personality and type of illness) and through their external environment (books, television etc.). This suggests that researchers were beginning to acknowledge that insight may be conceptualised through emotional and cognitive representations of information by the client and, given that these representations may be influenced by numerous external and internal variables, a complete assessment of client insight may be impossible to achieve.

Psychological approaches to insight

Psychological research has explored the impact of early Alzheimer's disease on the self and identity, for example through the impact on autobiographical memory, on the social presentation of self and through the way others relate to the socially-presented self (Sabat, 1995). Studies suggest that when the self is under threat, attempts are made by the individual to maintain control and self-esteem (Taylor & Brown, 1988). Coleman (1996)

highlights strategies used in the face of the threat of illness. These include ignoring, distorting, attributing symptoms to trivial causes, dismissing information and refusing to acknowledge the impact of illness.

Psychological and sociological literatures suggest that the dominance of biomedical conceptualisations of dementia are the cause of neglecting the subjective experience of dementia (e.g. Miesen, 1993; Kitwood, 1997), and historically, research has focused on cognitive functioning and clinical management, while neglecting insight, adaptation to increasing impairment and changes in social status (e.g. Cotrell & Schulz, 1993; Lyman, 1989). There also remains a lack of empirical information regarding the role of psychosocial factors as precipitators and mediators of behaviour in dementia (Cotrell & Schulz, 1993). These authors draw attention to the speculation in the literature regarding the psychosocial components of problem behaviour, for example the role of pre-morbid factors in shaping behaviour (e.g. Shomaker, 1987; Verwoerd, 1981). This suggests that people with dementia play an active role in shaping their responses to illness, rather than passively succumbing to the disease process.

Psychological research in the chronic pain literature highlights the need for phenomenological approaches aimed at understanding how the body and physical states are conceptualised and given meaning by the patient (Smith *et al.*, 1999). In this area psychologists have become aware that personal psychological constructs may be essential to understanding patients' experiences. In contrast, few studies have directly explored the perspective of the person with dementia. A pilot study by Froggatt (1988) interviewed three

women with dementia and while this study highlights the difficulty of interpreting 'fragmented thought', it suggests a viable alternative method of assessing awareness.

According to the psychodynamic literature, accessing deepest awareness of self represents insight, hence lack of insight is perceived as the result of repression, a defence against awareness of thoughts that may be intolerable to the client's ego (Weinstein & Kahn, 1955). Roback and Abramowitz (1979) suggest that achieving a deeper understanding may be damaging to the individual's perception of the future, and Sinason (1992) refers to the concept of 'secondary handicap', whereby the individual with dementia, and the rest of society is unable to face the pain of incurable degenerative illness. A decision not to know a diagnosis may be followed by blocking thoughts, and this process may further reduce insight.

A study by Balfour (1995) using the Thematic Apperception Test with 12 people who had Alzheimer's disease highlights the following themes; handicap, withdrawal and attachment need. While the results of this small study were not generalizable about the experience of dementia, it suggests that some form of awareness may be present, whether conscious or not, at different levels of functioning.

Psychoanalytic perspectives conflict with the view that there is a direct relationship between underlying organic change and actual functioning. These approaches suggest that the inner lived experiences are fundamental to the individual's understanding of illness, thus

challenging the perspective that describing inner experiences is impossible (e.g. Sinason, 1992).

Assessing insight

Currently there is a lack of well-validated measures for assessing insight in Alzheimer's disease. The different approaches to measuring insight include structured clinical interviews to measure awareness of cognitive deficits, for example the person's self-rating is compared with performance on objective neuropsychological tests; the person's reports of difficulties have also been compared with the primary carer's report (e.g. Feher *et al.*, 1991). Clinicians have attempted to rate awareness through the use of structured clinical interviews with the client (e.g. Auchus *et al.*, 1994), and predicted performance tests have also been used to measure awareness as the difference between the client's prediction of performance on a specific test and their actual performance on the test (e.g. McGlynn & Kaszniak, 1991). In contrast, some studies have adopted phenomenological approaches, for example Cottrell and Lein (1993) evaluated awareness by interviewing carers, and Bahro *et al.* (1995) observed behaviour, but few studies have explored the individual with dementia's perspective.

Methodological criticisms have been levied at these different approaches (Mullen *et al.*, 1996). The extent to which the discrepancy between the client and the carer's reports may be due to client awareness or to multiple social and psychological factors affecting carer reports has been criticised (Neundorfer, 1997). Research also demonstrates that carer ratings may be influenced by a wide range of factors, for example depression (e.g. De Bettignies *et*

al., 1990), and Michon *et al.* (1994) suggest that people with dementia occasionally rate their difficulties as more extensive than their carers.

There is a lack of data on the reliability and validity of clinical ratings, as well as the question of whether other tests of the domains measured would replicate the results. Some researchers (e.g. Larabee *et al.*, 1991) question the usefulness of relating questionnaire responses with performance on unfamiliar memory tests.

Neundorfer (1997) highlights the lack of attention to variability in awareness and the variance within groups limiting the diagnostic utility of a single awareness score. McGlynn and Schacter (1989) say there is a need for reliable information concerning the degree and quality of unawareness in various patient groups, and Neundorfer (1997) also draws attention to the wide range of awareness that can occur within a group of people with Alzheimer's disease, for example some clients will be more aware of their deficits than their carers; while others may generally agree with their carers etc. Furthermore, Wagner and Cushman (1994) demonstrate that awareness may vary across domains, and suggest that different levels of awareness need to be identified and described within and across domains, as well as to determine whether different types of awareness are tapped by the different measures.

Insight and caring

A study by Bergman *et al.* (1979) found that clients with dementia who lived in the community had significantly higher levels of insight than those in hospital. This led researchers to conclude that retaining insight enabled people to be better at accepting support and help. Further research suggests a significant correlation between loss of insight and level of carer burden (DeBettignies *et al.*, 1990). In the latter study, loss of insight was defined as the discrepancy between informant report and patient self-report. It suggests that with regard to the patients with Alzheimer's disease, loss of insight was significantly related to caregiver burden, as opposed to age, education, mental status, or level of depression. Loss of insight in this group was suggested to be significantly higher than the control group or the group with multi-infarct dementia, despite only having 12 subjects in each group. The patients with Alzheimer's disease were seen as lacking insight because they overestimated independent living skills, while informants underestimated patient capabilities, and this was suggested to relate to the degree of carer burden.

Insight, interventions and service provision

In terms of clinical management does having insight or a deep understanding of one's illness matter? In recent years the growth of interest in the concept of insight in dementia has been partly driven by a recognition of the need to empower people with dementia to take a more active role in determining their lives. This move is reflected in Community Care legislation

(DOH, 1994) and care managers now have a responsibility to ensure that the views of the person with dementia and their carer are heard as part of the assessment process.

Historically, the perception that people with dementia lack insight has meant that information pertaining to care has been sought from carers or third-party informants (e.g. Booth, 1985). Some researchers suggest that people with Alzheimer's disease are unable to comprehend questions or report on subjective states (Albert, 1998), and Mozley *et al.* (1999: pp. 776) cites Buchanan and Brock (1989) as referring to people with dementia 'approaching more closely the condition of animals than normal humans in their psychological capacities'.

It is hoped that improved understanding of dementia over the last 10 years has led to a more 'humanised' philosophy of care. Nevertheless, biomedical approaches continue to dominate care provision and where professionals perceive an individual to lack insight, or wrongly

estimate their level of functioning, this may have significant implications for the nature of the support and services provided following assessment and diagnosis. Lack of insight may also be perceived as the main cause of lack of co-operation with care provision, and this may have implications for potential paternalistic interventions of professionals (Fairbairn, 1993).

Greater understanding of the subjective impact of dementia may enable the development of appropriate interventions. Mullen *et al.* (1996) suggest speculatively that degree of insight may have implications for the best approach to the psychological aspects of care for people

with Alzheimer's disease, for example, they suggest that patients with good insight may benefit from reorienting approaches, while clients lacking insight may have better outcomes with validating forms of clinical interaction (Morton & Bleathman, 1991). A better understanding of the typology of personal insight may also enable the identification of clients in the early stages who might benefit from counselling services, cognitive-behavioural interventions (e.g. Husband, 1999), or may lead to the development of more creative treatments such as art and music therapy as a means of self-expression without the need for language (Norberg *et al.*, 1986).

Insight and diagnosis

Research needs to consider the relationship between insight and diagnosis. As Woods (2001) suggests, given that people with dementia are often not informed of a diagnosis, lack of formal insight is to be expected. In addition, research into diagnosis has failed to include the experiences of people with dementia (Pinner, 2000). A person's awareness of what is happening to them and the model of disclosure may have important psychological implications for way the individual and their family adjust to subsequent life changes. Furthermore, Cotrell and Schultz (1993) suggest that gaining an understanding of the individual's perceptions at an early stage may enable interpretations in the post verbal stage to be more meaningful if they are made in the context of the whole illness experience.

Conclusion

Attempts have been made to provide models of the phenomenon of insight within both psychiatric and neuropsychological literatures yet there remains a lack of empirical evidence to support a single theory in this area. A better understanding of this concept is needed because the biomedicalization of dementia has led to people with this illness being perceived as having impaired judgement and assumed inability to understand or verbalize experiences on practical or emotional levels. Consequently people with dementia are seen as passive recipients of care rather than as individuals actively seeking to find meaning in their experiences and developing coping strategies. A better understanding of the aspects of awareness might highlight whether different types of insight exist or whether there are certain psychological processes that determine the expression of awareness for an individual. Research has failed to clarify the role of factors such as pre-morbid intelligence, previous coping style, personality, previous knowledge and experience of illness, and how these contribute to the expression of insight. This knowledge would be of value to clinicians seeking to identify people who might benefit from specialist interventions, e.g. cognitive rehabilitation.

Quantitative studies have been aimed at identifying the predictors and correlates of lack of insight, and few if any clear findings have emerged. As indicated, the methods for assessing insight in Alzheimer's disease such as clinician global rating and calculation of discrepancy scores have been demonstrated as methodologically flawed. As Foley (1992) suggests, the research literature is dominated by wide-ranging, value judgements by clinicians who have

used questionnaires and rating scales to measure a complex phenomenon that varies according to the questions asked and who asks them. Where studies have defined insight as the extent to which the person with dementia is in agreement with their carer's perspective, they fail to take into account the complex interaction between relationship factors, previous life events, pre-morbid personality and mood.

While it may be important to understand the impact of neurological changes, models that relate solely to biological factors may be inadequate as they fail to take into account social context and psychological factors, in particular the potential role of psychosocial factors in the expression of awareness. One method for assessing insight that has been excluded from the literature is the phenomenological approach. Few studies have explored the perspective of the person with dementia, although there is some evidence that this is a feasible method of evaluating insight (Froggatt, 1988). The assumption that people with dementia are unable to provide valid and reliable information has been challenged (Keady et al., 1995), and early assessment and diagnosis may provide an opportunity to improve understanding of insight through a group of people who still have the cognitive skills to describe their experiences.

A phenomenological approach is needed to aid understanding of what is meant by insight and awareness, the psychological processes that contribute to these aspects and how they impact on the sense of self. This may improve our understanding of different coping strategies and defence mechanisms, and enable the application of specialist interventions. Furthermore, greater understanding of awareness in the early stages may have important implications for care in the later stages of the illness.

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APPENDIX 2

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Journal – Aging & Mental Health

SECTION 3. RESEARCH PAPER

RESEARCH PAPER

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Personal Experience In The Early To Moderate Stages Of Alzheimer's

Disease:

An Interpretative Phenomenological Analysis

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**PERSONAL EXPERIENCE IN THE EARLY TO MODERATE STAGES OF
ALZHEIMER'S DISEASE:
AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS**

ABSTRACT

Previous research has focused on measuring awareness in dementia with few attempts to define or clarify this concept, nor explore its meaning to the individual. This paper explores the experiences of seven people in the early to moderate stages of dementia. Interpretative phenomenological analysis illuminated some of the psychological factors that contribute to awareness and how these factors impact upon self-concept. It is suggested that clinicians and services need to pay greater attention to the phenomenological experiences of individuals with dementia. Four superordinate themes emerged: Relationship with memory, relationship with professionals, emotional experience of memory loss, and coping and maximising resources. Each category compares and contrasts individual experiences and suggests that awareness may be a complex concept that would be better understood by taking into account the psychological processes that contribute to individual awareness, and their subsequent impact on self-concept.

Key Words - Alzheimer's disease, awareness, carers, dementia, insight.

INTRODUCTION

There has been a growth of interest in the concept of insight in recent years. Despite growing recognition of the importance of awareness in clinical practice, the research literature is limited and definitions of insight remain confusing. In psychiatry the term is used to refer to a state of mind or mental act, and knowledge of insight is inferred from the way a client behaves and responds to their illness (Markova & Berrios, 1992). In the neuroscience literature the term 'anosognosia' has been used to conceptualise an individual's lack of knowledge of a condition (McGlynn & Schacter, 1989). However, in clinical practice some authors suggest that the meaning of awareness may be more complex than simply the knowledge that people have about their self and illness, and that insight may be conceptualised through emotional and cognitive representations of information by the client (Markova & Berrios, 1992).

In dementia research, the person's subjective experience of illness is a largely neglected area (Cotrell & Schulz, 1993; Bahro et al., 1995) and loss of awareness has been regarded as part of general cognitive deterioration. Early clinical reports include lack of insight or denial as a characteristic of Alzheimer's disease (Joynt & Shoulson, 1985), and early systematic investigations suggest that people with Alzheimer's disease may have less awareness of their general condition than those with multi-infarct dementia or Parkinson's disease (Danielczyk, 1983).

Studies suggest that as awareness may be lost at a relatively early stage in Alzheimer's disease; participants with this type of dementia are less likely to be depressed (Jenike,

1986). Numerous studies also indicate that where awareness is preserved in Alzheimer's disease, depressed mood is likely to co-exist (e.g. O'Connor et al., 1990; Sevush & Leve, 1993).

Despite attempts within both cognitive and neuropsychological literatures to provide a model of awareness, there remains a lack of psychological models or empirical evidence (Heilman, 1991). Research so far has failed to improve our understanding of why some people have a better understanding of what is happening to them, the factors that contribute to awareness or how awareness relates to mood and quality of life. Such information would be of value to practitioners, as well as gaining a better understanding of whether lack of information shared by professionals contributes to lack of insight (Rice & Warner, 1994).

Despite a considerable increase in the general public's knowledge of dementia over the last 10 years, the perception of memory impairment as an inevitable consequence of ageing persists, typically among older people (Fairbairn, 1997). Is telling yourself that your memory loss represents a normal part of the ageing process an adaptive coping strategy? Many questions such as these remain unanswered.

This study aims to explore the thoughts and emotions of people in the early to moderate stages of dementia; how they perceive their illness, the factors that influence the meaning of the illness to the individual, its impact upon their lives and how they cope, as well as exploring the thoughts of carers on these issues. It therefore adopts a phenomenological, 'insider's perspective' (Conrad, 1987). The specific methodology employed in the current

research is interpretative phenomenological analysis (IPA) (Smith, 1996a), a methodology committed to understanding the participant's perspective. It acknowledges however, that this has to occur through the interpretative analytic work of the researcher. IPA involves analysis of verbatim transcripts obtained from in-depth semi-structured interviews with participants (Smith, 1995). There is currently a lack of well-validated measures for assessing awareness in dementia and it can be argued that to fully explore the experiences of individuals, application of an intensive qualitative approach is required.

METHOD

Participants were identified by a nurse managing a day hospital, a community psychiatric nurse, a clinical psychologist and an assistant psychologist. The day hospital was based at a general hospital and provided multidisciplinary assessment that lasted six weeks. At the end of this time, participants and their main carer (where available) attended a case conference to learn the outcome of the assessment. For the purpose of this research, criteria for selection were: having completed an assessment either at a day hospital, or as an inpatient in the local hospital, or having been assessed by a clinical psychologist and a psychiatrist at home or at an outpatient clinic. Participants needed to fall within the category of possible Alzheimer-type dementia¹, and be able to engage in conversation. They did not need to be aware of the diagnosis to participate. Interviews were conducted in English or Welsh according to the person's language preference.

Participants were either approached by a professional or received a letter from the researcher inviting them to participate. All received a phone call from the researcher and those who agreed to participate received a home visit to clarify any issues and obtain written consent.

Table 1. Sample characteristics:

Participant	Age	Marital Status	Place of Assessment
Mrs Edwards	73	Married	Day hospital
Mrs Jones	76	Widowed	Day hospital
Mrs Holland	78	Widowed	Day hospital
Mr Stuart	82	Widowed	Day hospital
Mr Evans	89	Single	Inpatient at hospital
Mr Rogers	76	Married	Out patient clinic
Mrs Johnson	75	Married	Out patient clinic

Table 1. provides a sample profile. Seven participants agreed to take part in the research. As maintaining an overall mental picture of each participant was important, a sample size larger than 10 is not recommended (Smith et al., 1999). Within qualitative research it has been argued that assessing sample size is not appropriate, rather it is the applicability of concepts that is important (Conrad, 1990). The aim is to gain an ‘insider view’ through interpretative analytic work and given the intensity of this methodology and the volume of rich data, sample sizes are generally small (Smith et al., 1997). In addition, no new themes emerged from the data after detailed interpretative analysis and thus it was not deemed necessary to increase sample size.

Table 2. Brief summary of Clinical Dementia Rating Scales (CDR) scores:

Participant	CDR
Mrs Edwards	Mild dementia 1
Mrs Jones	Mild dementia 1
Mrs Holland	Moderate dementia 2
Mr Stuart	Mild dementia 1
Mr Evans	Mild dementia 1
Mr Rogers	Questionable dementia 0.5
Mrs Johnson	Mild dementia 1

Table 2 provides a brief summary of participant's Clinical Dementia Rating Scale scores (CDR: Hughes et al., 1982). On average participants had been assessed six months previously (range from one week to 18 months). According to key workers, the diagnosis had only been shared with three clients. These were clients that had attended a case conference at the day hospital.

Interviews lasted on average one hour with participants. The semi-structured interview procedure was based upon the methodology detailed by Smith et al. (1995), and involved open-ended questions covering areas of interest such as the circumstances that led to assessment, awareness and experiences of memory difficulties, experiences of being assessed and subsequent impact on lives. These questions acted as a guide and were adapted to enable further exploration.

All interviews were fully transcribed from audiotapes. These verbatim transcripts acted as raw data for analysis and transcripts were read repeatedly to obtain a sense of the participant's accounts. Starting with the transcript of the first interview - notes were written on the left-hand margin to summarise significant or interesting comments as well as highlighting initial interpretations, preliminary connections and associations. On the right-hand margin emerging theme titles and key words to capture the quality were documented. These themes were transferred to a separate sheet and examined for connections or clusters. The master-theme list from the first interview was used to begin the analysis of the second interview and this procedure was conducted for each interview.

As themes became clustered they were related back to the original transcripts in order to check that the connections explained the data. This was in order to ensure that the themes emerged from the transcripts rather than being constructs predicted by the researcher. The process was cyclical and where new themes emerged from the data the transcripts were revisited for other instances of them. From the list of master themes four super-ordinate themes emerged. These are considered in relation to the existing literature in the discussion section.

Explicit criteria for recognising themes included; agreement of themes in several transcripts, the need for themes to make sense to participants when fed back on the second visit, themes also needed to make a distinct contribution to the analysis alongside other themes, although they formed part of a superordinate theme.

In order to ensure the validity of the analysis, participants were contacted to feed back themes. This has been suggested as a method of ensuring validity in qualitative research (Elliott et al., 1999). In addition, two researchers examined a few of the transcripts independently to discuss and agree on theme categories. This provided a check for internal coherence and verified that the analysis was systematically achieved and supported in the data.

RESULTS

This section presents the four super-ordinate themes that emerged from the analysis, which were: relationship with memory, relationship with professionals, emotional experience of memory loss, and coping and maximising resources.

Relationship with memory

All participants were able to recognise the onset of short-term memory loss but there were individual differences in their relationship with memory, the way they interpreted loss and their response to this process. Participants varied in their awareness of having memory difficulties, from those who sensed something was not quite right to those who were acutely aware of having Alzheimer's disease and the long-term consequences of the illness:

Slipping

Mrs Edwards was aware that she had '*minor lapses in day-to-day memory*' but she normalised these as ageing and discounted them in comparison with other long-standing health problems and bereavement. She could not explain why she had been referred for assessment and denied any association between her current difficulties and an aunt who had Alzheimer's disease:

"My memory not being as good as it was... well that is me ageing... I don't worry about anything now... (Mrs Edwards)

Revealing and seeking confirmation

In contrast, Mrs Johnson was aware her memory difficulties were not part of the ageing process. She had hoped to receive a diagnosis from the psychiatrist at an outpatient appointment, this had not been forthcoming and she had no idea what was wrong:

“It’s the knowing that something’s wrong but not knowing what that bothers me... I mean I went so see my doctor, he sent me to the hospital but the doctor there just said nothing really... just that there’s nothing they can do for me... I get very upset and frustrated with myself...”

Similarly, Mr Evans suspected he had Alzheimer’s disease but had not received a diagnosis:

“...the GP referred me... He could see that my mind wasn’t well, not the same... could see there was something wrong with me... he sent me to the hospital for them to see what it was that was causing me to feel like this...”

He perceived his illness as an inevitable part of ageing and had been expecting to develop the illness as other close family members had died from Alzheimer’s disease.

Confirmation

Where participants had received a diagnosis there was considerable variation in their awareness of dementia, their level of understanding and the subsequent impact on self-concept:

“I’ve had heard the term ‘Alzheimer’s’ used before - I thought it meant that your memory was gone... it gets worse, eventually you get a complete loss of memory and you don’t know what your doing and then die. That’s what is going to happen to me...” (Mr Stuart)

Being at the case conference did not guarantee participants knew that they had dementia, for example Mrs Holland continued to talk about her difficulties in a slipping way.

Therefore, external confirmation did not necessarily guarantee internal confirmation:

“I had such a good memory... Just I can’t remember what year it is and my memory’s not as good... it’s old age isn’t it? I’m sure that there are many people like me...”

Mr Rogers talked at length about having Alzheimer’s disease and his experiences of caring for his mother. He attributed his difficulties to old age but presented in a good mood and his response was to keep going for as long as possible:

“If I’m going to go like my mother... I am not going to worry and just carry on as much as I can... maybe it will all go in the end and I won’t be able to remember a thing...”

Relationship with professionals

Being left in the dark

Need for information varied considerably. Most participants were unable to recall the outcome of their assessment, even within a week of the case conference. In general participants highlighted *‘lack of adequate information’* regardless of the model of disclosure.

Where a diagnosis was provided this was not accompanied by a prognosis:

“No, I can’t remember a thing that was said at the case conference... It was OK but I can’t remember who was there. I had seen the doctor before I can

remember that. Nobody told me anything about my memory or the problems I'm having, nor did they explain what this Alzheimer's means." (Mr Stuart)

Several participants had driven long distances to learn the outcome of their assessment.

They reported not receiving a diagnosis or adequate information. In one case a participant was angry with the psychiatrist for telling him never to drive again without providing an explanation. Another participant reported that the psychiatrist had not been listening:

"I was furious I felt I'd gone all the way there and he didn't take any notice, he didn't say anything...we'd made an effort to go there for nothing... I came out and said what was that?... He didn't say anything about my memory nor give me any advice on it... too much interested in his office... putting the table into place, more interested in that than seeing me... I didn't feel important to him."
(Mrs Johnson)

Feeling patronised

Mr Stuart denied feeling depressed but expressed a need to talk about his experiences. He said that rather than having his needs met at the day hospital he felt '*patronised*':

"I'd just get people to talk to me, and talk sense... not patronise me. They do their best I know, it is very difficult... there's no treatment for this... it's been no experience other than having some company and... eight of us meeting and talking, playing word games - I found intensely boring."

Positive experiences

Not all experiences of being assessed were negative and some participants reported that the day hospital had enhanced their feelings of self-worth. Positive experiences were: talking to people with similar experiences and engaging in activities, e.g., quizzes and memory games:

“I’m much happier than I used to be, I was very serious as if I was carrying the world’s worries on my shoulders.” (Mrs Edwards)

Participants who saw the clinical psychologist at home valued this opportunity:

“Seeing Dr James (psychologist) things were better because it was different talking you know... she is very nice... talking is very important because I haven’t been able to talk to anybody.” (Mrs Johnson)

Emotional experience of memory loss

Loss

This theme emerged in multiple domains. Firstly, participants described the fear and frustration associated with loss of control:

“My memory switches off and then it comes back again. It’s terrible when it comes back it’s like I’m drowning, I’ve jumped in the deep end and I can’t get control over the situation...” (Mr Stuart)

“Feeling like I’m sinking slowly... things slipping away... finding crosswords very difficult to do ...as if anything that needs me to use my mind has come to a full stop.” (Mr Evans)

For some participants having to go into long-term care was representative of loss of control:

“I’m going from here to a home I think... got to go into a home... I don’t want to but I have to... can’t cope... it’s not living... it’s just being nursed and existing and I don’t care for that at all.” (Mr Stuart)

Loss of control related to fears participants expressed of losing their identity:

“I have an identity that is different when I’m in this state of dreaming, it’s dreaming isn’t it? That’s all. It is a very frightening experience... when you realise that you think that it’s real... when you’re in the trance, your brain forgets and switches off, switches off reality and you can’t think... This illness makes me aware my brain is giving me false impressions of reality...in the middle of it I say to myself ‘this is not real’, ‘not the real world I’m in’... but I’m very conscious, gradually, and it’s a struggle - but I manage to come back...” (Mr Stuart)

“If I go like a vegetable just make sure I go, I don’t want to live like a vegetable, I don’t want to live like one... just let me go.” (Mr Evans)

Many participants appeared to be grieving for lost skills and this had an impact on self-esteem and quality of life:

“I’ve dropped many of my interests and activities. I did all the flower arrangements and growing plants... but I had to give it up last year because I couldn’t do it. It was me, I didn’t feel myself and my memory was going... it has stopped me from enjoying myself as much.” (Mrs Johnson).

Participants were also concerned for how their skill losses may affect significant others:

“It’s not right for him, it’s not right to have to look after me. He’s in his sixties and I’m in my early nineties and I’ve finished my life.” (Mr Stuart).

Many participants who were aware of their memory difficulties related skill loss with low mood :

**“Not being able to do anything, you know? ...makes you feel low... so pointless... I’ve been losing control these last few months and going very down, depressed they say... I feel like things are in such pain, pain...”
(Mr Evans)**

Unresolved issues

For some participants awareness of memory difficulties evoked memories of other unresolved losses. These losses mainly concerned the death of children or close relatives in difficult circumstances. In some cases participants had not discussed these losses for many years:

“I do think back... had a little boy but he died... that was terrible losing him so young... my husband never recovered... these things I haven't talked about for a long time...” (Mrs Jones)

Coping strategies and maximising resources

Compensating

Participants referred to using compensation strategies to keep going for as long as possible:

“I do develop strategies to cope with the illness... I know that I compensate and this will enable me to carry on for some time.” (Mr Stuart)

Most participants were aware that carers were attempting to compensate for memory lapses to maintain normality in everyday life:

“I think he might cover up and jolly things along... He does compensate for me with the things I find hard to do, but I would like to know what he really thinks you know... he is gradually doing more for me.” (Mrs Johnson)

Being able to be normal

Participants felt that one of the most important factors to maintaining psychological well-being was to feel '*normal*', or part of society:

“When I’m talking to people I feel quite normal sometimes... normal is being able to say what you want to say - when you’ve got things to say you know, talk... when you can talk to someone and have a conversation and make them understand you...” (Mr Stuart)

Participants also felt the need to carry on as normal for as long as possible:

“I go to the farm every day you know... As a rule I usually know exactly what I have to do on the farm... I’ve never known anything else, farming has been my life. I just carry on... not to worry and carry on as much as I can.” (Mr Rogers)

Acceptance

Most participants who were unaware of having dementia accepted decline as part of the ageing process and those who were aware of their diagnosis appeared to have accepted the inevitability of decline:

“...you know it’s coming and you can’t do anything about it... you have to give up and let it happen...” (Mr Davies)

Blocking negative thoughts

Most participants reported distracting or blocking out negative thoughts:

“I try not to think about things and I try to keep busy...” (Mrs Jones)

“...I don’t think about my memory much... I’d drive myself mad worrying.” (Mr Rogers)

Minimisation

Many participants attributed their problems to the ageing process, so minimising its impact:

“...I don’t think there’s much I can do about it, it’s just old age... years ago there wasn’t the same food, nourishment that there are these days...” (Mrs Holland)

Some participants would talk about being unable to complete tasks they regarded as trivial (e.g. completing forms) but would report being able to engage in interests (e.g. making tapestries, knitting or gardening) despite a lack of evidence that they were engaging in these activities.

Selective comparison

Participants appeared to be struggling to maintain definitions of the self that were positive and worthwhile:

“I see some people in that Day Centre who are very poorly... I try to go around and talk to them all... some are so pathetic they don’t have anything to say to you... I’m lucky I can talk and enjoy a conversation... it gives you a boost to think there are people worse than you.” (Mrs Jones)

Withdrawal

In contrast to endeavouring to be normal, several participants who described feeling low and losing confidence, reported gradually disengaging from people and activities as their memory deteriorated:

“I was talking to people but I shut up when I get stuck and can’t get the words out you know... makes me go quiet... I don’t have the confidence...” (Mrs Johnson)

Planning for the future

Some participants had not made any plans for the future as they regarded this as the role of close relatives. In contrast, those who talked with insight into their diagnosis and its consequences felt they needed to make arrangements:

“I want to leave things tidy for my son and family, grandchildren... I am trying to plan them now... not to leave them any problems to clear up after me... I just don't want to leave behind problems for people I love...” (Mr Stuart)

DISCUSSION

Empirical research to date has failed to take into account variability in individual awareness and the factors that contribute to awareness (Neundorfer, 1997). Research attempts to classify people with dementia as falling into one of three groups: no insight, good insight or partial insight, with little exploration of what this means (e.g. Reed et al, 1993). In this study all the participants were able to recognise the onset of memory difficulties and, therefore, it could be argued simplistically that, if being aware or having insight represents awareness of the commonly agreed features of dementia, all the participants had a degree of awareness. Nevertheless, this study highlights marked differences in the intensity of individual awareness of what was happening, impact on self-concept and the defence and coping mechanisms used.

Participants had multidimensional experiences, and attending to the psychological processes and constructs suggest that, rather than representing a unitary concept, insight is a complex, dynamic, shifting entity which may be better conceptualised through emotional, cognitive and social representations of information by the client, taking into account a number of external and internal variables (Markova & Berrios, 1992).

Insight or awareness are not an 'all or nothing' phenomena, some participants recognised difficulties with short-term memory but appeared to be denying any association with Alzheimer's disease or dementia, some labelled their difficulties, while others were acutely aware of the threat the illness presented to one's self and identity. For some participants awareness related to grief, mood and quality of life. In these cases loss of self

represented a fundamental part of suffering, whereby the person is aware of their identity disintegrating without any control over this process.

In this study personality differences in the need to maintain control over life events was evident. Some participants reported being content with a primary carer or professional taking control over decisions or life events. However, in marked contrast, feeling in control for some participants appeared to be an important aspect of affirming a person's sense of identity. Models of stress-control relationships place an emphasis on cognitive factors, i.e. the attributions an individual makes for a relevant stressor can lead to learned helplessness (Abramson et al., 1978). This suggests an individual's perceived level of control may predict mood and quality of life, and if service providers disempower people who are already struggling to maintain control over their self and identity, this may lead to further withdrawal.

Some participants who did not meet the criteria for depression appeared to be struggling to come to terms with their illness. They may have benefited from some form of counselling or cognitive-behavioural intervention (e.g. Husband, 1999). Furthermore, when coming to terms with loss, some participants attempted to interpret the disruption in a way that it made sense in the context of their life history. This suggests a need for professionals to take into account biography and the personal context of memory loss (Kitwood, 1997).

There is a need to explore the *meaning* of illness for each individual. Factors such as previous knowledge and experience of dementia, support systems, personality, previous

coping style, attributions and beliefs may also be important to take into account when attempting to gain an understanding of individual awareness during assessment. According to the literature on chronic illness patients use a wide range of strategies to adapt to life changes. Moos (1989) suggests that responses to illness are mediated by individual appraisal of illness crisis, personal and cultural characteristics, physical and social environment, as well as illness factors. In dementia research, there remains a lack of empirical evidence regarding the role of psychosocial factors as precipitators and mediators of behaviour, and in clinical practice people with dementia continue to be perceived as passive individuals succumbing to cognitive deficits, rather than individuals who have a unique perception of their illness and a complex repertoire of pre-morbid coping skills (Cotrell & Schulz, 1993).

In this study, psychosocial factors played an important part in the strategies participants used to attempt to maintain control. These had an impact on the expression of awareness, for example minimising losses, distorting and ignoring information. These are consistent with the strategies Coleman (1996) identifies as being used to respond to the threat of illness, for example, refusing to acknowledge its impact, attributing symptoms to trivial causes, ignoring, dismissing or distorting information. Blocking thoughts about the future may be consistent with Sinason's (1992) reference to 'secondary handicap' in dementia, whereby society is unable to face the pain of an incurable degenerative illness: hence a decision "not to know" a diagnosis may be antecedent to blocking thoughts, and this may further reduce awareness.

Participants also refer back to skills in the past and this may have further amplified their sense of loss. Withdrawal of social contact was an undesirable strategy, but was used because of the personal costs associated with engagement.

There was considerable variation in experiences of being assessed and diagnosed in this study. Some participants had positive experiences of coming to a day hospital, but the need to explore ways of responding to individuals is also highlighted. References to feeling 'patronised' and 'not being listened to' in the face of struggling to maintain control, suggest the need for better understanding of the biographical context of the person's life history, and ensuring shared control over the direction of the assessment, as identified by Keady and Bender (1998). This may enable services to respond better to the lived experience of early dementia.

Some participants had positive experiences, for example being supported by a community nurse or the clinical psychologist who had been involved with the assessment, however many highlighted communication barriers with some psychiatrists and they felt 'patronised' or 'not listened to'. Those that had attended a multi-disciplinary meeting thought that this had been of some value, but they also reported being unprepared for seeing so many professionals in one room. This is consistent with other studies (Rogers et al., 1993; Bains & Vassilas, 1999). The latter authors suggest that procedures need to be clearer, whereby clients are fully informed of the format and agenda for the case conference. This is recommended as one of the roles of the key worker, and they suggest that a carefully worded letter or information sheet may be of some benefit.

In this study few participants had received a diagnosis, despite several reporting that they wanted a diagnosis and information. None were able to recall information at the case conference and where a diagnosis had been communicated this was not accompanied by a prognosis, nor were participants offered an opportunity to talk about the diagnosis after the case conference. Participants who had been assessed by a clinical psychologist valued this opportunity to talk and be listened to. In contrast, most participants who had seen a psychiatrist reported feeling disempowered, did not receive sufficient information, and expressed anger at being told to give up activities without any explanation. Pinner (2000) suggests that rather than being a one-off event, disclosure should be a dynamic process that is a fundamental part of patient care. Other psychiatrists also suggest that exchange of information should be patient-led and where possible staged over several appointments, with full support for the client (Rice & Warner, 1994).

In conclusion, paying attention to the phenomenological experiences of individuals with dementia highlights some of the factors that professionals need to take into account when making judgements about a person's insight. As indicated, this concept is more complex than simply knowledge an individual has about their illness, and it may be important to assess factors such as individual beliefs about ageing, previous knowledge and experience of dementia, nature of support available, pre-morbid coping mechanisms, as well as models of diagnostic disclosure and how they impact on awareness etc. Combining knowledge about these factors, how they relate to awareness, in addition to information on neuropsychological deficits, may provide a more accurate understanding of the factors that contribute to individual insight.

As part of the assessment process, exploring the factors that contribute to individual awareness, as well as taking into account the person with dementia's perspective, we are 'humanising care' (Goldsmith, 1996), thus rather than disempowering people, services work towards understanding the meaning of the illness to the individual in order to maximise a person's ability to cope and find meaning in their lives. The early stages of dementia present an important opportunity for this work. Furthermore, knowledge obtained at these crucial stages may be relevant to understanding the process of loss of awareness, and the relevant cognitive and emotional factors in the later stages (Cohen, 1991).

ⁱ Criteria for possible Alzheimer's disease as established by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA).

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APPENDIX 3

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APPENDIX 3

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Dementia: The International Journal of Social Research and Practice

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Taken from the 'Report of the NINCDS-ADRDA Work Group'

DATA ANALYSIS SAMPLE:**Relationship with memory****Slipping**

S2a.p15/L12-16

I had such a good memory... my character is still the same... that doesn't change does it? Just I can't remember what year it is and my memory's not as good... I have to write everything down... I write everything in my notebook... I guess that's what one has to do as one gets older...

S2a.p15/L22-26

I had such a good memory but now my memory's going... mind you I'm 78 now... you can't really tell can you? Just I can't remember what year it is and my memory's not as good... it's old age isn't it... it has to be just old age? You get to a certain age and I'm sure that there are many people like me... I would have thought that most old people?...

S3a.p26/L5-14

It was a good memory in fact my husband relied on my memory a great deal yes... his memory is better than mine now... he keeps saying you've forgotten this and that... but only little things you know... it just happens with age...

S1a.p6/L4-7

I get lost, the same with if you take me shopping in Tesco's and if I turn round and lose sight of my daughter - I've not got a trace of which way she went. And yet, at one place, one time, I would have remembered all that - but it's just gone completely... I can remember then but I can't

remember... now if I went in the other room and I would think had I shut the cat in here? I'd think where's the cat. I can't remember from getting out the door to turning round... everything just goes complete. Just lost, just worse because I can sit down and then I will ask them - whatshername... what day is it? and that sort of thing... My mind swings from one thing to another. Wait a minute? It just seems to be a blank half of it...

S1a.p8/L7-9

I can remember a lot of things that have happened years ago better than I can remember things that have happened a day or two ago, you know what I mean? because I can remember... wait a minute... it's gone...

S1a.p5/L8/10/15-20

I used to do a lot of sewing...I can't even sew a button on now I've not got the... it's daft I've got a sewing machine up there and I'd do everything on it wouldn't I?... now I can't even sew a flaming button...

S6a.p44/L3-7

I find it difficult to concentrate... I've stopped making things like my embroidery and my gardening - I was always out in the garden. We do have a good size garden... but my mind's not as clear as it used to be... it's not good...

S2a.p17/L11-13

No one in my family has suffered from memory problems - Mum had problems with her heart... her memory was like everyone else's memory as they get older... it got worse of course as she got more frail... but I don't think I have that.

S2a.p15/L20-23

Well it's old age isn't it?... I don't know... it has to be just old age.

- You get to a certain age and I'm sure that there are many people like me... I would have thought... that most old people?

Revealing and seeking confirmation

S3a.p24/L9-13

I went to that unit the doctor sent me up there last September. He didn't say why he was sending me there but I believe it was a sort of psychology test from what I gathered... my memory is getting a little you know... but my doctor has kept an eye on me regularly, last year he had a pamphlet from the hospital and he thought he'd send me there...

S1a.p1/L8-10

I went to my doctor because I was mithery I suppose... my memory's all kaput isn't it?...I'm not very good, I'm very forgetful. I'll say to Anna something or other and then I'll turn round, get two steps and say 'what was it?' or 'what did I come for?' and it's only a yard and it's gone... it just goes completely so I know it can't just be my age...

S4a.p29/L10-19

Yes... it was the pain - the GP referred me... my doctor you know? He could see that my mind wasn't well, not the same... could see there was something wrong with me... I went to see my doctor first to tell him that something was wrong and then he sent me to the hospital for them to see what it was that was causing me to feel like this...

S7a.p51/L2-4

Nobody has ever explained to me what is causing my memory problem - I've decided from the outset that if that's what wrong with me...whatever it is... Alzheimer's or what? old age maybe? or perhaps they're both the same things?...

Confirmation

S7b.p51/L25-31

Why?... Well I have no idea... Alzheimer's disease? The forgetting only happens when I go to the shop and want to fetch a few things. What I mean is well...before I started having problems I could go to the shop and remember all the things that I needed to get.....I could remember without a list you know? ...that's why I went to the doctor, because I knew I wasn't right..

S5.p37/L15

Alzheimer's disease. That's what it's called. It's just a name... I had heard about it, but I think one of the doctors told me what it was - it's Alzheimer's disease... I had heard the term used before - I thought it meant that your memory was gone - it's just it's destroyed the loss of your memory. It gets worse yes, definitely, it does not get better, oh no... eventually you get a complete loss of memory and you don't know what your doing and they die.

S4a.p32/L7-11

Gradually dying and having a cardiac arrest... you die slowly of heart disease with your heart stopping slowly, that's what happened to my sisters and that's what is happening to me... yes having heart disease is the main part of the illness and then you forget... you know it's

coming and you can't do anything about it... you just have to give up and let it happen...

S5a.p30/L28-30

About my sisters... two had Alzheimer's disease and the one who's still alive has heart disease... I have a good understanding of Alzheimer's disease as I've been reading... Dad died with Alzheimer's disease but they didn't say that at the time, they just said that he died of old age but looking back it was Alzheimer's disease, it's just that they didn't call it that in those days. It didn't say Alzheimer's disease on the death certificate... I don't think they knew what it was... the doctor just put cardiac arrest...but maybe today it's different...

S5.p34/L12-15

I've got that Alzheimer's it affects your memory um.. I remember some things but I forget recent things, you know immediate things. I've got a long-term memory but not a short-term memory.

S4a.p31/L8-10

It's this Alzheimer's disease... I have this inherited disease. I've managed to avoid getting cancer, something gets you, you know, but I've got Alzheimer's disease instead...

S4a.p30/L16-26

I know about this Alzheimer's disease - it's to do with old age... both my sisters were in their eighties and Alzheimer's disease happens when you get older... that's what I am you know - very old now. It's part of getting older... that's what I think happens to you when you get older, it's happening to me, and it's getting worse. I can see it in front of me and I have read all about it... and I've seen this Alzheimer's disease in

my own family... I've seen a lot of people with it and that's why I think it's happening to me now. I suppose it doesn't happen to everyone... no, no... but I've got the disease because I'm so old and I'm going the same way as my sisters did. You have to prepare yourself, accept it as it's going to happen, whether you like it or not... accept it...

S4a.p30/L6-14

There's no explanation from the doctor, maybe they don't know themselves do they? They just don't have the time to tell you.... things are getting worse you know... I used to be so active and now I can't enjoy my interests, I've lost all my interests. It's a lot of losing with this memory thing. I've lost my two sisters you know to that things - what is it? - Alzheimer's disease. They both had that... they lost their memories and couldn't talk... the two sisters with Alzheimer's disease and one has old age.

S5.p37/L8-15

There are people whom I knew, a friend of mine, clever man you know, very clever, he was one of the best brains that ever went to Oxford. He was brilliant and suddenly his brain went - he got this Alzheimer's disease and he couldn't work at all, hopeless. He's dead now isn't he? He died recently, a few years ago, it just went. I wasn't as clever as he was, I know I spoke languages but oh dear me... I have the same as him - Alzheimer's disease. That's what it's called. It's just a name!

S5.p37/L7-8

I don't know what's causing it? Just I'm getting old and the brain is switching off.

S6a.p51/L2-8

Nobody has ever explained to me what is causing my memory problem - I've decided from the outset that if that's what wrong with me... whatever it is... Alzheimer's or what? old age maybe? or perhaps they're both the same things?... but whatever it is if I'm going to go like my mother I am not going to worry about it... just let it happen...that's my decision - not to worry and just carry on as much as I can... Maybe it will get worse? and maybe it will all go in the end and I won't be able to remember a thing...

Relationship with professionals

Being left in the dark

S5.p37/L16-20

I would have liked to have had it explained properly - they just tell you the name 'Alzheimer's disease'. I have to go on what I know. I didn't get any information on it at all. I was told nothing by the doctors I would have liked to have known about it that's all. I didn't want to know a lot but...

S3a.p25/L1-11

My husband expected a little more but um everybody was very pleasant but it wasn't what you might say what we expected. I thought they might have spoken to us about my case... They didn't say very much we just sat and listened... It was rather difficult, I don't mean to be rude.

S6a.p50/L15-21

All he (*psychiatrist*) did was turn to me and say “you can never drive again.” I’ll never forget that. I had such a shock I forgot to ask why. Nobody had suggested anything like that might happen... I couldn’t believe it... nobody explained why, they just sat there and told me I can never drive again. I was so flabbergasted I couldn’t really be sure about anything else that was said when we were with him... I don’t think he said anything much to me just...”you can never drive.” I have no idea why he stopped me from driving. Maybe I could understand if he had told me why... there must be some reason but what it is I couldn’t tell you?

S6a.p45/L1-15

It was about 8:00 in the morning when we went to see him (*psychiatrist*). I was furious I felt I’d gone all the way there and he didn’t take any notice... he didn’t say anything... we’d made an effort to go there for nothing... I came out and said what was that?... if he’d said like my own doctor would say... that must be difficult for you. It was a waste of time... came all that way early in the morning. We’d made an effort to go there for nothing... I came out and said what was that... he didn’t say anything about my memory nor give me any advice on it... he’s too much interested in his office... putting the table into place... more interested in that than seeing me... I didn’t feel important to him...

We thought perhaps there would be an explanation... like with certain illnesses, this is due to so and so or whatever, and you understand that and then you have got the complete picture... but when he told us there was nothing they could do without explaining what the problem was.

Feeling patronised

S5.p40/L8-12

I'd just get people to talk to me, and talk sense... not patronise me. They try to do their best you know, it is very difficult... it's been no experience at all other than having some company, there was, yes, about eight of us meeting and talking, playing word games that I found intensely boring. I don't care for word games it was just an unnecessary exercise and my brain was being taxed to try and solve questions. I didn't see any point in it, you see? I didn't see and point in it at all, anyhow I joined in anyway and carried on, but I didn't think much of it at all.

S1b.p10/L24-25

...I had all the patronising talk. I had to come in front of everybody and they told me about Alzheimer's disease...

S1b.p11/L24-28

Very patronising as If I knew nothing at all. Which I suppose maybe Joe Bloggs on the street doesn't um ... and I said 'It's all right I like to be patronised now and again, you know'.

Positive experiences

S2b.p18/L13-14

I enjoyed going to the Day Hospital. I worried about it before but enjoyed it once I was there...

S5.p42/L17-19

It was helpful coming to the hospital as far as I had companionship... It was the company and that's the most important thing for me.

S7b.p53/L13-15

Dr James made me feel special you know... just by listening and the fact that she'd just come here to see me...

Sa.p24/L21-24

Somebody would talk to us and there was drawing and a quiz and what else did we do?... we went out in the cars... I think one morning we did go out for a run in the car and then another afternoon we had somebody trying to show us about making cakes... I know about that! I mustn't laugh but it was fun, and then we used to have drawing and different things.

S3a.p25/L19-21

I'm much happier than I use to be, I was very serious as if I was carrying the world's worries on my shoulders, so in that way I've improved and I appreciated going up to the hospital last year very much indeed... especially seeing Dr Edwards (*trainee psychologist*).

S6a.p45/L16-

Seeing Dr James things were better because it was a different talking you know... she is very nice... talking was very important because I haven't been able to talk to anybody... well you don't... I don't know it's hard to explain to people why you don't feel yourself... explaining your memory but everywhere you go people go on about their memories but I say oh you're like me you know ...I don't think about my memory much - I'd drive myself mad worrying.

S6a.p50/L25-31

Dr James came out to the house... she was a lot of help to me. I couldn't really tell you why she came here in the first place... something to do

with the other doctors? I have to be honest I can't really remember..
 you'll have to ask my wife she always remembers these things - I have
 to rely on her...I can't remember the circumstances that led to seeing Dr
 James... I would tell you if I could but I'd be lying if I told you I could
 remember.

Emotional experience of memory loss

Loss

S5.p42/L3-12

How would I describe it? I would describe it as forgetting, forgetting
 where you are and, what you're doing, not being aware. I forget my
 identify when I have these trances but it's like I adopt another identity...
 So I don't say I forget my identify, I just change it I go into another
 identity, it's hard to explain... I have an identify that is different when
 I'm in this state of dreaming, it's dreaming isn't it? that's all. It is a very
 frightening experience... when you realise that you think that it's real...
 when your in the trance, your brain forgets and switches off, switches
 off reality and you can't think... That makes me feel confused, but I
 don't feel that bad about it - it's just a damned nuisance, damn nuisance
 you can't do things, normal things...

S4a.p25/L25-27

My memory switches off and then it comes back again. It's terrible
 when it comes back it's like I'm drowning, I've jumped in the deep end
 and I can't get control over the situation...

S5.p35/L15-16

It was quite frightening... I ended up weeping over this. It just that oh...
 knowing what to do is so difficult, especially on your own.

S5.p36/L20-32

I'm feeling all right except that I forget, I forget, I forget things sometimes... I forget temporarily only for say five minutes and then it comes back to me you see. I can do things you know, I can do things like getting dressed. I forget for less than five minutes, I forget and then I stop, remember how to do it and it's OK. It is very stressful for me! I can talk to you and make conversation with you but when I'm getting dressed or doing something, some function of that kind I will... I got up this morning very late so I hurried, I got dressed and I got my things on. I was going fast and I was efficient but suddenly I'm blank, I forget my next step... now then if I stop and don't let it... don't panic and don't let it worry me, I'll remember again and it will come back. My memory will click into gear again and it will come back. It's really difficult to say. I'm alright now. When you go I shall make myself a meal, a frozen meal....

S5.p39/L25-32

I haven't got any quality of life when I get this Alzheimer's disease... I'm living in a trance, I think it's real, that's the trouble... I think it's reality but it's not reality and sometimes, like in the middle of it I say to myself this is not real, not the real world that I'm in, but I'm very conscious... gradually... and it's a struggle, but I manage to come back... I have to come back to the idea that I'm lying in bed and that's where I am lying in bed, I'm not able to get up... it's a trance a non-real trance for a while and it takes time after it starts... I don't know... it's difficult to describe...

S5.p42/L3-12

I forget my identify when I have these trances but its like I adopt another identity you see so I don't say I forget my identify I just change it I go into another identity it's hard to explain... I have an identify that is different when I'm in this state of dreaming it's dreaming isn't it? that's all. It is a very frightening experience... yes... when you realise that you think that it's real... well when your in the trance, your brain forgets and switches off, switches off reality and you can't think... it just switches off reality. That makes me feel confused, confused, but I don't feel that bad about it its just a damned nuisance, damn nuisance you can't do things, normal things...

S4a.p31/10-16

I don't feel there is a future... I know there isn't a future... give me strength! everything is leaving me.

S4a.p30/L6-14

It's hard to say you know... Yes, I've been losing control these last few months and going very down, depressed they say... I feel like things are is such pain, pain ...

Feeling like I'm sinking slowly... things slipping away... finding crosswords very difficult to do... as if anything that needs me to use my mind has come to a full stop.

I'm going from here to a home I think... got to go into a home... I don't want to but I have to... can't cope... it's not living... it's just being nursed and existing and I don't care for that at all.

I have an identity that is different when I'm in this state of dreaming, it's dreaming isn't it? That's all. It is a very frightening experience... when you realise that you think that its real... when you're in the trance, your brain forgets and switches off, switches off reality and you can't think.

S2b. p21/L9-12

I just get so frustrated sometimes with it all, I lose my temper and end up feeling like having a good cry.

S5.p42/L13-14

I cried that night because of the mess, taking that medicine, it was the shame, the indignity, fear of being out of control... an awful experience.

S3.p16/L18-20

He said "If I go like a vegetable just makes sure I go, I don't want to live like a vegetable, I don't want to live like one... just let me go."

S1a.p9/L8

Yes, my quality of life has changed... very much so, well I suppose it's old age - I don't know

S6a.p43/L19-27

...I've dropped many of my interests and activities I did all the flower arrangements and growing plants for sales in the spring and I would, you know, grow them here but I had to give it up last year and I used to help with the WI. I did a lot with the blind but I stopped it last year because I wasn't well... I couldn't do it... I'd done enough and I gave it to someone else to do. I'd done it for 10 years. It was me - I didn't feel myself and my memory was going. I have also been getting days when I feel depressed...

S2a.p15/L6-13

Problems with my mind make me feel low. I get very down-hearted when I think about the problems I have with my memory. I feel very depressed when I can't remember such and such... especially given that I used to learn recitations and poems and things like that...

S2a.p15/L25-31

Yes I had a good memory. I was always competing in Eisteddfods, I used to recite poetry all the time... I enjoyed that... it was many years ago now... I suppose I shouldn't be blowing my own trumpet but I did have a very good memory... I've always been very active you know... I always had a very active mind and that's why it's so frustrating now that my memory's getting worse and I feel bad with myself that I have to put everything down on paper.

Unresolved issues

S2a.p16/L7-16

...I do think back sometimes... I had a little boy but he died... maybe if I'd had a son he would have been a support to me? but you never know do you? That was terrible losing him so young.. my husband never recovered (*Repeated story twice in depth*).

S4a.p31

Makes you feel low... so pointless (*repeats story of father and sisters dying with Alzheimer's disease*).

S3a.p23/L1-4

...I lay in bed for four and a half years before my son... he's the only one... was born yes I had to lie on a bed for four and a half months because there were complications you see I was grieving a lot about the

loss of my brother especially and my mother, we were a very closely knit family, this is fifty years ago now and I think myself because...
(*provided a detailed account of life events and losses*).

S2a.p14/L18-21

I do become very depressed at times here... thinking about the past... I don't cry as such...but of course it's just... answering yourself isn't it? or talking to yourself?

Coping strategies and maximising resources

Compensating

S5.p39/L6-10

I do develop strategies to cope with the illness but I haven't had any advice from anybody. I suppose I'd like that... I know that I *compensate* and this will enable me to carry on for some time...

S6a.p46/L1-6

Sometimes I think he doesn't catch on quite how bad it is you know... I think he might cover up and jolly things along... but when... well... he does *compensate* for me with the things I find hard to do, but I would like to know what he really thinks you know... he is gradually doing more for me...

S7a.p52/L14-15

Somehow I guess I cope by Anne compensating for me. It's frustrating but I don't seem to be able to do anything about it... that's the way it is...

Being able to be normal

S5.p38/L14-22

When I'm talking to people I feel quite normal sometimes... normal is being able to say what you want to say - when you've got things to say you know? talk?... what's not normal is not knowing what to say um... but when you can talk to someone and have a conversation and make them understand you, and I can understand them. I have no difficulty with my neighbour across the way... taking me shopping, he does things for me, have a conversation with him, we go shopping and he takes me to the bank and things like that, does a lot of things for me.

S5.p40/L14-17

My friends don't, they're not aware of it at all when they're talking to me... not at all, we talk quite normally and we... Like tomorrow the friend I'm going out with I told you about, we'll go out and it'll be quite normal, except that he has to drive as I can't drive myself, and we have a meal... quite normal.

S5.p40/L23-28

When I'm with people, with my friends particularly... they just talk to me normally and advise me on this that and the other. If I could have them with me all the time... these friends I'd be... of course, if my wife was with me I'd have been normal... behaved normally, and been alright - I wouldn't forget things.

S7a.p49-50/L33

I go to the farm every day you know?... As a rule I usually know exactly what I have to do on the farm...I use lists and the son leaves one pinned up for me everyday. I've never known anything else, farming has been my life. I just carry on - no reason why not. I can't do

anything physical with the exception of occasional light work. I go to the yard to meet the dogs, feed the lambs, see to the silage, sweep out the barn... I can't manage to learn anything new like using new machinery or driving one of the modern tractors... I used to be able to drive them but I wouldn't like to risk it now. It's handy for my son to have me going to the farm to see to things for him... I've never known anything else, farming has been my life. I just carry on... not to worry and carry on as much as I can.

Acceptance

S2a.p17/L4-9

It gets worse yes, definitely, it does not get better, oh no... eventually you get a complete loss of memory and you don't know what your doing and they die. But um that's what is going to happen to me... yes, it doesn't worry me...

You know, you know... let's face it you have to be ready to accept that the end is coming. There's a saying you know... what is it? I think it's 'A man without...um... a man's speed of life is measured by 70 years and anything over 70 is living on borrowed time'. That's what I am... yes.. living on borrowed time... Yes, anytime over 70 is borrowed time.... *(silence)*

S6a.p51/L2-8

Nobody has ever explained to me what is causing my memory problem - I've decided from the outset that if that's what wrong with me...whatever it is... Alzheimer's or what? old age maybe? or perhaps they're both the same things?... but whatever it is - if I'm going to go like my mother I am not going to worry about it... just let it happen...that's my decision - not to worry and just carry on as much as

I can... Maybe it will get worse? and maybe it will all go in the end and I won't be able to remember a thing...

Blocking negative thoughts

S2a.p14/L15/23-27

...You have to make the most of life don't you?... that's the way things are... I try not to think about things and I try to keep busy...

S6a.p42/L25-28

I get very upset and frustrated with myself...I worry and just think that it's going...then I have to let it go again...that's how I cope - I worry about it and then I have to shut off...that's the only thing to do isn't it? You'd go mad if you thought about it all the time

S7a.p45/L16

...I don't think about my memory much - I'd drive myself mad worrying.

Minimisation

S5.p37/L7-8

I don't know what's causing it? Just I'm getting old and the brain is switching off.

S1a.p5/L15-20

I noticed that where I used to wipe things and do a lot - I look at them after and I can see I haven't got them as clean as I should and I keep having to put them back in to do but eh... I suppose that's old age, and I know these places are old but oh, I don't know... I used to do a lot

of sewing...I can't even sew a button on now I've not got the... it's daft I've got a sewing machine up there and I'd do everything on it wouldn't I?

S1a.p7/L11-14

It (*diary*) helps because at least I know what day it is. But do you know if forget it the one night I wouldn't know what it is the next day. But I don't think there's much I can do about it, it's just old age. Years ago there wasn't the same stuff, same food and nourishment that there are these days because I can remember them doing one egg between three.

S3a.p26/L1-4

My Aunt had memory problems... it may be in the family - I don't know (*laughs*) She used to wonder around and she didn't know where she was... but that is old age I think (*laughs*) I haven't come to that yet I think.. I try and keep quite all right but I do forget what my husband says, little things (*laughs*)

S3a.p25/L22-23

My memory not being as good as it was... well that is me ageing, that's age. I get a little pressure there. I don't worry about anything now... not at all...

Selective comparison

S1a.p5/L5-6

...it gives you a boost you think there are people who're worse than you.

S2a.p16/L22-24

I see some people in that Day Centre who are very poorly... I try to go around and talk to them all... some are so pathetic they don't have anything to say to you... I'm lucky I can talk and enjoy a conversation.

S3a.p16/L26-30

I don't know what is wrong with them... I'd have thought it was just old age but some of them are very young you know! There's one very stout one who can't say anything to you... and he can't be very old... I like to go around and have a word with them all... even if they can't say anything and you just have to sit there.

Withdrawal

S2a.p14/L24-25

I don't really remember when these things happen... I don't cry, no, I just go quiet...

S6a.p43/L4-9

It's difficult when other people come in and talk to me and... I get so... I don't think my friends here know anything - that my memory is bad... I don't speak a lot... We don't have a lot of family here... it's when I go out to the social on Thursday and uh... I was talking to people but, I shut up when I get stuck and can't get the words out, you know, so it makes me go quiet... I don't have the confidence...

S6a.p43/L14-16

Well at the moment I don't talk you know... and uh....it can be quite isolating in some ways. I haven't been a big talker I was always the good listener but I only really talk to my husband now.

S6a.p43/L27-28

It has stopped me from enjoying myself as much but that's the way it is
(*talked about withdrawing from activities she had enjoyed*).

Planning for the future

S5.p41/L6-14

What I would like is for me to go in my sleep sometime... but I want to leave thing tidy for my son and family, grandchildren... I am trying to plan them now.. I'd like to have them... not to leave them any problems with regard to my possessions... I'd like to leave them tidy.. not leave people problems to clear up after me. I'd love the property to all be sorted... I don't mind for myself at all... there's no fear of death. I will die, and I know I'll die, and I'll be happy about it but I just don't want to leave behind problems for people.

S5.p36/L13-17

Well I'll just have to sooner or later, I don't want to go into a home, not just now. Well, if I'm under nursing care in a home I'm fine but I'm just doing nothing and my brain goes to sleep and I'm not thinking. It's so lovely because everything is done for you and uh... but it's not living really, it's just being nursed and existing and I don't care for that at all.

S5.p38/L2-5

Well not too much for him, it's not right for him, it's not right to have to look after me. He's in his sixties and I'm in my early nineties and I've finished my life... I've had a good life and I am really waiting to go now... there is no future. I still get pleasure out of life, I like living but I won't mind dying either, at all...

S1a.p10/L3-5

I've always said to you don't hesitate to put me in a nursing home...

Well I feel it's not fair to my daughter and the kids sometimes...

S4a.p31/L18-21

I don't know ... I'm going from here to a home I think... got to go into a home... I don't want to but I have to. It's been a big shock to come to the hospital... I'm waiting for a sign to tell me what to do next... you see a lot of people in the hospital... I don't know...

SECTION 4. CRITICAL REVIEW

CRITICAL REVIEW

Background

This study emerged from a preliminary audit of client experiences of attending a day hospital. This audit demonstrated that people in the early stages of dementia can talk with clarity and insight into their experiences, and that these accounts can provide valuable information to inform clinical practice and improve standards. It was evident from a literature review that few studies have explored the role of psychological factors in the expression of insight or the personal meaning of illness for the person with dementia (e.g. Cotrell & Schulz, 1993; Keady, 1996).

Previous research on insight failed to include the role of psychological and psychosocial factors which contribute to the expression of awareness. These studies focused on psychiatric and neurological factors, for example localisation of sites of potential lesions associated with awareness (e.g. Michon et al., 1994). Development of new models of insight which include psychosocial and psychological factors, in addition to cognitive and neurological factors, may be important because of the clinical implications.

It was intended that the results of this study would be presented to professionals working in older adult psychiatry services as well as to the Alzheimer's Disease Society - Wales.

Methodology

Given that few studies have explored this area an intensive qualitative methodology was needed to enable a full exploration of meaning (Osborn & Smith, 1998). Interpretative phenomenology (IPA) was deemed to be the most appropriate method of data analysis (Smith, 1996a).

Recruitment

It had been anticipated that recruitment would be straightforward owing to the small sample size needed for qualitative research (given the volume of work it is not recommended that IPA is used with sample sizes larger than 10; Smith 1996b). Identifying participants who did not have communication difficulties or multiple health problems was difficult, and identifying suitable participants was further complicated as the majority of people with dementia come to the attention of services in the later stages of illness (Alzheimer's Disease Society, 1995). Therefore, obtaining access to people who were willing to participate in the research and who could give consent was difficult. In addition, other research studies at the day hospital coincided with this study and it was deemed to be inappropriate to approach the same subjects.

The study had intended to include referrals from the memory clinic, but unfortunately as this was a new service and uptake was slow at the time of recruitment, it was not possible to include participants in this service. In order to compensate for loss of a contrasting model of assessment, two participants were identified from the caseload of a local clinical psychologist and one client was an in-patient on an assessment ward at the local hospital.

The recruitment process was further complicated by a request from the new senior house officer in psychiatry that clinical psychologists should obtain written approval from each of the consultant psychiatrists before access to information on participants at the day hospital. This had not been an issue in previous research studies. Obtaining written consent delayed the process of recruitment by three weeks.

Recruitment was also difficult owing to the departure of the assistant psychologist in the day hospital. At the time the research began a new assistant was appointed but it took six weeks to identify suitable participants through this service. This lack of suitable participants, followed by the arrival of a new senior house officer, meant that the time-scale was delayed. Once these barriers had been overcome the Christmas period intervened and only two interviews had been completed by this time.

Sample

It had been intended that the sample would include eight people with Alzheimer's disease but, owing to the time-scale and lack of participants who met the selection criteria, only seven participants were included. The original study had also intended to include the views of carers. This had not been possible owing to the available word count. Participants were identified by different professionals and, given that the sample was biased towards people with good communication skills, it may be suggested that good verbal skills implies retained insight.

It is not possible to be absolutely certain that all the participants had possible Alzheimer-type dementia. Several participants and carers had been told they had a diagnosis of dementia or Alzheimer's disease. But participants were in the early stages of illness and it is not always possible to distinguish the different dementias, furthermore subtypes of Alzheimer's disease may exist (Feher et al., 1991).

Unfortunately, it was not possible to compare participants on the same battery of psychometric tests as different psychologists had undertaken the assessments. The study may have been improved if the same standardised tests had been completed by participants. This was not possible owing to the time-scale. If participants had been referred through the memory clinic, as originally planned, this data would have been obtained.

Interviews

In terms of interview context, all the interviews took place in the participant's home, where they generally reported feeling more relaxed and less threatened, talking in their own environment. The disadvantages included long travelling distances (on average 60 mile return journey) and distractions in the home environment, for example household pets and telephones.

It was assumed initially that people in the early stages of dementia would be reticent to talk about their experiences and fears for the future. In most cases the first few minutes of interviews were crucial for establishing some trust and allaying any suspicions. The

interviewer was relieved that she had experience of working with people with dementia and their families, and in several cases when families realised that they could speak in the Welsh language, perceived communication and cultural barriers were immediately overcome. As indicated in the study, many families highlighted their experiences of communication difficulties with English-speaking professionals. They reported that being able to speak in their own language enabled them to talk more openly and honestly about their experiences, and they felt that a Welsh-speaking professional would have a better understanding of their situation.

Cotrell and Schulz (1993) suggest that carers may be protective of relatives and fearful that participation may expose them to confrontation and distress. There was some evidence that carers were initially protective and concerned about the nature of questions, for example whether the term Alzheimer's disease would be used. As with good clinical work, establishing good rapport with all concerned may have been the most essential part of the study. In one case a participant decided not to participate owing to stress.

Prior to each interview questions were discussed with the participant and their family. Given the emotional content of the interviews it was important that questions were appropriately sensitive. It was vital to establish what the individual knew and understood about the diagnosis. Starting an interview by asking what participants felt about having *dementia* would have been unethical because not all were aware of their diagnosis. If this word had been inappropriately disclosed it may have caused considerable distress to the participant.

Some researchers highlight the need to offer a tangible benefit for participation in order to improve recruitment of people with Alzheimer's disease (e.g. Berg et al., 1982). Williams et al. (1988) have drawn attention to the need to provide specialist services for people who agree to take part in research. In this study this was not necessary as participants were already in touch with services. However, despite access to services, few participants had been given an opportunity to talk about their feelings or experiences. It may be unethical to undertake research of this nature unless the interviewer is a professional with some counselling skills. These skills were used to reflect, clarify and summarise the information disclosed (Coyle & Wright, 1996). It was important to ensure that participants had a mechanism for accessing additional support if they needed further counselling.

Many participants provided moving accounts of their thoughts and feelings. This was an emotional experience for the interviewer as well an intense learning experience. Cohen and Eisdorfer (1986) have suggest that provision of an open environment for the person to talk often moves the individual to a stage of greater openness and acceptance of the disease. Being prepared to listen to unpleasant feelings and thoughts, active and careful listening for client preparedness, and slow and gentle confrontational style have been recommended as vital for maintaining client comfort (Cohen & Eisdorfer, 1986).

Process issues

It was important to be aware of personal views and emotions that may arise in the course of this type of research. In this study there were occasions where the researcher was confronted with issues that related to one's own losses or fears about death and dying.

This may highlight some of the reasons why many professionals avoid facilitating an open, honest discussion about dementia.

Withdrawal from some participants was difficult as they had shared inner thoughts that they had not had an opportunity to discuss elsewhere. As indicated, being clear about the limitations of the study was important, but in some cases participants were referred to an appropriate professional, for example the community nurse. Discussion of these issues in supervision was important.

Data collection

Transcription took approximately eight hours for each hour of interview. This was further complicated when interviews were in the Welsh language as the tapes had to be transcribed in Welsh and translated into English. This was time consuming. While it was tempting to have some help with transcription, this was not deemed to be appropriate as listening to the tone of a person's voice enhances meaning and understanding of context .

Data analysis

It had been intended that the data would be inputted into *Nudist Software* for analysis using IPA. This was not possible as the software was only available in the department for data stored on an 'AppleMac' computer, and a longer time-scale would have been required to become familiar with this package.

IPA was used in this study because this methodology is reflected in the research question. The research question was aimed at revealing patterns of meaning, interpretation and understanding which were inherent within the individual experiences. Elliott (1995) suggests qualitative research methods are the best approach to understanding participants' perspectives and defining phenomena in terms of experienced meanings and observed variations. Smith (1994) also suggests that the strength of qualitative research is the way it operates at a micro level, and its ability to explore the content of particular individuals' beliefs and responses, as well as illuminating processes operating within models. This was particularly important in this study owing to the lack of research on the perspective of the person with dementia and, as indicated, previous quantitative studies had failed to illuminate or document the subjective perceptual processes that are used to make sense of illness.

Validity

Some papers highlight criteria and guidelines for undertaking qualitative research in psychology (e.g. Henwood & Pidgeon, 1992; Smith, 1996b; Elliott et al., 1999). However, some researchers criticise the development of a single set of guidelines for qualitative methodology (Reicher, 2000). With regard to issues of validity and reliability in this study, draft results were scrutinised by two other psychologists. Transcript samples were provided to the research supervisor and another trainee clinical psychologist¹ in order to obtain a consensus on themes. The themes which emerged appeared to be

¹ Trainee clinical psychologist was familiar with IPA.

consistent with the supervisor and other professionals' experiences of working in the service under consideration.

Follow-up interviews with participants and carers were aimed at providing a form of credibility check. Henwood and Pidgeon (1992) suggest that the danger with this method is the power differential between researcher and participant, i.e. participants may feel too disempowered to challenge feedback from a professional. This is an important issue which arises in psychological work with older adults. In this study several of the carers had been health professionals, and both participants and carers presented with strong views regarding issues discussed. Follow-up sessions were important because of the memory difficulties participants experienced, and discussion of the themes that emerged from transcripts provided a method of checking internal validity. In addition, areas that were not fully covered in the first interview were clarified.

Clinical and research implications

It is suggested that the subjective experiences of people with dementia are excluded from research owing to the presumed difficulties in obtaining valid and reliable information from the individual (Cotrell & Schulz, 1993). This study challenges this assumption and questions adherence to rigid methodological standards without examining their relevance to people with dementia. In general, this study achieved its main aim to explore individual differences in awareness and the factors contributing to this and suggests that including the person with dementia's perspective can help professionals to understand the impact and course of the illness.

Research studies have begun to move away from relegating people with dementia to the status of object rather than as being a legitimate contributor to the research process (Cotrell & Schulz, 1993). Nevertheless, in terms of service delivery there remains a long way to go. Where professionals make generalisations that people with dementia lack insight, their voices will be excluded from service provision (Keady, Nolan, Gilliard, 1995), and opportunities for improving the care that people receive in the later stages will be lost.

One of the areas which merits further research concerns the views of people with dementia on diagnosis. In the study only two participants had been informed by the psychiatrist of their diagnosis, while several participants reported that while they wanted and anticipated a diagnosis, this had not been forthcoming. Johnson et al. (2000) found that only 40% of geriatricians and older adult psychiatrists regularly told patients a diagnosis and 20% saw no benefit of giving a diagnosis, yet 72.5% would want to know themselves if they had dementia. These results are consistent with other studies (e.g. Rice et al., 1997; Vassilas & Donaldson, 1998).

Research into diagnosis excludes the views of people with dementia (Pinner, 2000). There is little evidence that disclosure of a diagnosis results in long-term harm (Rohde et al., 1995), and studies of older people suggest that 90% wanted to be informed of a diagnosis (e.g. Holroyd et al., 1996). The main reasons cited concern being able to make plans for care and for sorting out family matters. Pinner (2000) suggests that with medical advances, living wills, issues pertaining to enduring powers of attorney, choice of care

services etc., being told a diagnosis may contribute positively to the process of psychological adjustment by allowing participants to express their fears and anxieties.

Moody (1995) opposes informing people of a diagnosis of dementia, as it is suggested that they immediately forget this information. In the present study the individuality of participants, the considerable variation in awareness and understanding of what was happening, suggests that, as Pinner (2000) highlights, providing a diagnosis should not be a one-off event. Rather than being told on one occasion at the case conference or outpatient appointment with a psychiatrist, disclosure should be a dynamic, ongoing process and an integral part of patient care.

Limitations

One of the weaknesses with this study concerns sample size. The study had aimed to include the views of carers and professionals on awareness. This was not possible because as mentioned previously of the format of the large scale research project. The format of the present study meant that the results of qualitative analysis had to be condensed to 2000 to 3000 words. Given the volume of relevant, rich data that emerged from transcripts, including further in-depth perspectives was impossible in the existing word count.

A possible source of bias was the time lag between interviews and attending case conferences or visits to the psychiatrist. This may have resulted in some participants

inaccurately recalling their experiences, or selectively recalling negative experiences. Other researchers highlight this issue (e.g. Bains & Vassilas, 1999).

Future research projects

To provide a more complete understanding of the issues and concerns facing individuals in the early stages of dementia, quantitative methodology may be used to complement and expand on the results of this study. Comprehensive data on cognitive functioning (e.g. awareness of memory deficits and nature of cognitive impairment), as well as data on mood, pre-morbid personality and perceived quality of life may provide a more in-depth understanding of insight. These measures could be provided to people with dementia, carers and professionals in order to gain a more complete picture. Cross-sectional and longitudinal research designs may also enable clinicians to acquire a better understanding, as well as gathering information on changes in affect, functioning and awareness over time.

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SECTION 5. MAIN APPENDICES

STATEMENT OF WORD COUNT

<u>Thesis component</u>	<u>Words</u>
Title	15
Main abstract (summary)	249
Ethics proposal	3378
Literature review	4838
Research paper	4999
Critical review	2969
	Total = 16,448

<u>Components of appendices</u>	<u>Words</u>
Contents section (excluding abstract)	564
Tables (section 3)	97
<i>References:</i>	
Literature review references	1707
Research paper references	899
Critical review references	660
Appendix 1	4251
Appendix 2	1120
Appendix 3	8829
Main appendices (section 5)	300
	Total = 19,400