

APPRAISAL AND COPING PROCESSES IN WOMEN WITH EARLY-STAGE ALZHEIMER'S DISEASE

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ABSTRACT

Psychological research has often ignored the self-reported experience of people with Alzheimer's disease. Their personal narrative of what is happening to them has often been overlooked on the assumption that cognitive impairment renders their account invalid. This qualitative study examined appraisal and coping processes in women with early-stage Alzheimer's disease. Semi-structured interviews were conducted with nine women. The partners or carers of the women were interviewed separately. The interviews were audio-taped, transcribed and analysed using Interpretative Phenomenological Analysis. This generated eleven themes describing how the women understood and managed their difficulties. These are grouped into three higher-order themes of Connectedness, Protective Strategies and Acceptance. The women experienced memory problems as a threat to connectedness or sense of self, derived from attachment to family and friends, affiliation with social roles, familiarity with surroundings and a sense of continuity with the past. A Level of Connectedness Model of the appraisal and coping processes of women with early-stage Alzheimer's disease is presented, which shows a tension between disconnection and coping strategies that relied on maintaining a connection with others and the environment. This places coping in an interpersonal framework, where the ability of the women to maintain a sense of self is inherently dependent on the readiness of others to facilitate connectedness. The results are discussed with reference to psychological theories, models of coping with chronic illness and previous qualitative research on coping with dementia, including a consideration of possible gender differences. The findings provide a useful focus for good clinical practice and psychosocial interventions that consider well-being in an interpersonal context.

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INTRODUCTION

Psychological research has often ignored the self-reported experience of people with dementia and mainly relied on information provided by carers. The person with dementia is often relegated to the status of object rather than legitimate contributor to the research process. Their personal account of what is happening to them is overlooked on the assumption that cognitive impairment renders their contributions invalid. The same process effectively excludes the person from influencing her treatment and care. One of the most distressing things that happens to a person with dementia is that others ignore or avoid her on the assumption that she will not understand or remember what is being said. A research agenda that ignores the experience of the person with dementia reinforces this position.

The exact nature or pattern of difficulties in early dementia will vary from one person to another. However, in the early-stages of Alzheimer's disease people are able to comprehend what is happening and actively try to make sense of this. During the 1990s researchers began to move beyond the biomedical approach and recognised the value of listening to subjective accounts. Cotrell and Schulz (1993) conclude that much can be gained from a systematic study of patients' views regarding their illness and care. Cohen (1991) suggests that knowledge of the subjective experiences of people with dementia positively impacts on their care and well-being.

Autobiographical accounts have been published in which people with Alzheimer's disease described their personal experience of cognitive decline. For Robert Davis (1989) the immediate impact of Alzheimer's disease was his inability to continue to

function as a priest. With help from his wife he was able to describe not only his loss of skills, but also his fight against feelings of betrayal by God.

Diana McGowin (1993) gave a description of her determination to fight against early onset dementia. Whilst still in her early 50s, dementia began to impact on her ability to carry out her social roles as mother, grandmother and in her career. Early symptoms were at first attributed to stress. Her account also illustrates how others around her attempted to cope with the diagnosis, often by denying there was a problem.

Both the McGowin and Davis accounts may be interpreted as struggles to maintain a sense of self. An awareness of loss in dementia requires a redefinition of self and identity; that is, an alteration in how the self is perceived and evaluated. Coping procedures play a key role in this process. Before reviewing the literature on coping in dementia, it is useful to first examine the different conceptualisations of dementia. This will be followed by a consideration of how the theoretical contributions of health psychology, and an examination of qualitative research in maintaining self-identity in chronic illness, may inform our understanding of coping with dementia. The impact of dementia on self will then be considered, followed by a review of awareness in dementia in relation to depression and anxiety. The presentation of models of coping with dementia and previous qualitative research in the field will be followed by a consideration of self-identity and ageing in women. Based on the rationale derived from these areas of previous research, the research question to be explored in this study will then be presented.

1.1. DEMENTIA OF ALZHEIMER'S TYPE

Dementia is a process of deterioration in mental functioning. The International Classification of Diseases (ICD-10: WHO, 1992) defines it as a syndrome of brain

disease, which is usually chronic and progressive. It is characterised by a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. A primary requirement for diagnosis is a decline in memory and thinking in such a way as to impair the activities of daily living.

This study focuses on Alzheimer's disease, a dementing disorder, usually of middle to late life. It is characterised by its insidious onset and progression. A diagnosis cannot be made by laboratory tests, although these are important for identifying other causes of dementia that must be excluded. The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA) research criteria for a diagnosis of probable Alzheimer's disease (McKhann *et al.*, 1984) require that dementia is established by clinical examination, screening tests and neuropsychological assessment. There should be deficits in two or more areas of cognition, including a progressive worsening of memory. The criteria require the onset of cognitive decline to be between age 40 and 90 (usually after the age of 65). Alzheimer's disease cannot be diagnosed if consciousness is impaired. It is essentially a diagnosis of exclusion as it necessitates the absence of systemic disorders or other brain diseases that could account for the deficits. Among the more common disorders that must be excluded are manic-depressive disorder, Parkinson's disease, multi-infarct dementia and drug intoxication (Morris, 1999). A probable diagnosis may be supported by impairment in activities of daily living and altered patterns of behaviour. Evidence of cerebral atrophy on computerised tomography (CT) or magnetic resonance imaging (MRI) would provide further support for the diagnosis (Jobst, Suarez & Miller, 1999). However, a definite diagnosis can only be made from histopathologic evidence on autopsy.

Miller and Morris (1993) describe the decline in memory in dementia in three stages. In Stage 1, mild memory lapses occur, but cause relatively minor problems and are often attributed to the effects of normal ageing, stress or depression. The person may forget errands, or fail to pass on messages and becomes disorientated in unfamiliar surroundings. A major feature is the impairment of episodic memory; that is, memory for personally experienced and time-specific events, such as conversations with people. According to Morris (1999), deficits in episodic memory account for much of the temporal and spatial disorientation in dementia. Episodic memory testing is therefore an important part of neuropsychological assessment. A person with dementia will show difficulties in such tasks as recall of prose passages, lists of words and sentences. In Stage 2, these problems become more pronounced and start to have a significant effect on daily living activities. This is the point at which medical help is often sought, usually prompted by a relative or friend. Difficulties will include forgetting familiar people and disorientation in time and in familiar surroundings. The person becomes increasingly unable to keep track of daily events and becomes more dependent on others. Forgetting close relatives and confabulation mark Stage 3. Here memory problems will lead to a concern for the person's safety. The person may start to wander or forget to turn off appliances. At this stage the person may forget details of personal information such as their previous occupation or the names and composition of their immediate family.

Although this stage description of progressive cognitive deterioration provides a useful overview, there is considerable variation in the profile of decline. The extent to which stage models capture the individual's actual experience of dementia will vary. The difficulties people experience will differ not only according to the type of dementia they have, but variation is also evident within types of dementia. For many people the first symptoms in the early-stages of Alzheimer's disease will be loss of recent memory. This may be followed by deficits in language, praxis or visual

perception. Yet in some patients with Alzheimer's disease, difficulty in finding words, impaired visual perception or apraxia will occur before impairments in recent memory (Morris, 1999). Furthermore, apart from its increasing frequency, it may at first be difficult to distinguish deficits in episodic memory from normal forgetfulness. Although deficits in episodic memory are the most significant impairment in Alzheimer's disease, for many people the first noticeable symptoms will be a loss of attentional control, that is the ability to combine two tasks such as carrying on a conversation whilst attending to another activity (Baddeley, Bressi, Della Sala, Logie & Spinnler, 1991).

Of particular relevance to this study is a consideration of how cognitive impairment in early-stage Alzheimer's disease may impact on the person's ability to communicate her difficulties in the context of a research interview. During the course of an interview memory difficulties may be expressed in various ways: word finding difficulty, talking in a repetitive way, inability to remember names and recent events. These kinds of difficulties may be affected by mood, motivation and environmental factors. The person's awareness of this may cause them to become frustrated or embarrassed. Killick and Allan (2001) describe how cognitive impairment can lead to a creative or inventive replacement of words that are no longer available to memory. Examples of this are the use of figurative speech such as metaphors. Whereas variability in language use may be a feature of fluctuating cognitive ability in vascular dementia, in Alzheimer's disease this variation is more likely to be a consequence of tiredness and interpersonal factors.

Killick and Allan (2001) therefore point to the need to interview people with dementia at a time of their choosing. The pace and rhythm of conversation should be adjusted to the person's ability. Silences and responses that are out of synch with the questions asked indicate a need to slow down the pace of the interview. Clarke and

Keady (2002) recommend an interview style that avoids asking about frequencies or time sequences. Spending time to build rapport is essential for validating the individual, which may help reduce anxiety. Careful consideration should be given to the influence of the interviewer's attitude and behaviour on the person's responses.

1.1.1. Continuum or dichotomy: dementia and normal ageing

Cognitive decline, like dementia, becomes increasingly common with advancing age. Memory functioning becomes less efficient as a person approaches his or her late sixties. It is relatively more affected in the very old, which explains why diagnostic criteria do not allow for a dementia diagnosis to be made after the age of ninety. Mild memory impairment in normal ageing has variously been described as Benign Senescent Forgetfulness (BSF) or Age-Associated Memory Impairment (AAMI).

Brayne, Gill, Paykel, and Huppert (1995) used the Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) to monitor cognitive functioning in a longitudinal study of a large elderly sample. A small decline was found in all age groups, which increased significantly with age. Very few of the oldest participants in the sample maintained a high score. The decline was greater in women than in men. This finding is consistent with epidemiological studies of dementia, where the higher incidence of dementia in women may be accounted for by higher rates of male mortality.

There has been some debate whether cognitive deficits in the general elderly population are similar to those seen in people with dementia. Histological studies have found an association between the amount of amyloid plaques and neurofibrillary tangles, and cognitive deficits. However, the same pathological changes have also been found in individuals who did not appear to have dementia.

What appears to distinguish people with dementia from the general elderly population is the amount of pathology (Hart & Semple, 1994). It has therefore been suggested that dementia may be regarded as one extreme on a continuum of cognitive decline in normal ageing (Huppert & Brayne, 1994). Alzheimer's disease is conceptualised as representing the lower end of a normal distribution of age related changes within the population. The distinction is in the rate at which change occurs. Evidence for this continuum model is limited, however, and little is known about possible risk and protective factors.

It has been argued that the 1970s saw the medicalisation of old age and a redefinition of the term Alzheimer's disease (Adelman, 1995; Cheston & Bender, 1999a; Estes & Binney, 1989). Previously the term Alzheimer's disease was used to refer to the relatively rare condition of pre-senile dementia. According to Katzman and Karasu (1975), Alzheimer's disease (pre-senile dementia) and senile dementia were the same condition, which they suggested should henceforth be referred to as Alzheimer's disease. Fox (1989) has argued that by reframing senile dementia as an illness with a high mortality rate rather than an aspect of normal ageing, the biomedical establishment was effectively able to secure more funding.

Gubrium (1986) interprets this differentiation of deterioration in dementia from that of normal ageing as a social construction that reflects society's difficulty with images of unacceptable decay and mortality. Thus images of ageing as a general period of decay have been transformed into images of disease that unlike ageing might be potentially curable and will not necessarily affect everyone. The unfortunate consequence of this is that society has become predisposed to interpret 'abnormal behaviour' in terms of disease, and neglects seeing any meaning in the behaviour of the person with dementia.

1.1.2. The disease model of dementia

The disease model attributes deficits in cognitive functioning directly to neurological impairment. Rapid advances in our understanding of brain structure have led to a differentiation of dementia into various kinds of disease and degenerative processes. The classification of dementia types (and subtypes) is complex and the list is growing. A distinction is generally made between three types of dementia, Alzheimer's disease, vascular dementia and 'mixed' type dementia (Cooper, 1997; Field, 1998). Other possible causes of damage to brain structure include degenerative diseases (e.g. Parkinson's disease), infections (e.g. Creutzfeld-Jacob disease, meningitis, neuro-syphilis and AIDS-related dementia), toxins (e.g. alcohol related brain damage and poisoning by metals) and damage induced by head injury (e.g. boxing). Distinguishing between the types of dementia is important for treatment considerations.

In Alzheimer's disease there is shrinkage of the brain associated with enlargement of the ventricles and sulci. Other neuropathological markers of Alzheimer's disease include senile plaques, neurofibrillary tangles and granulovacuolar degeneration. Alzheimer's disease probably accounts for around 70% of dementia diagnoses. However, variability in clinical presentations has led some to suggest that Alzheimer's disease is an umbrella term, encompassing different pathological processes. Furthermore there appears to be a considerable overlap in neuropathological changes that may be expected in normal ageing and that found in Alzheimer's disease (Esiri, 1991).

As the term vascular dementia suggests, in this type of dementia cerebral atrophy is associated with a lowered blood supply to the brain, generally due to cardiovascular disease. It is thought to account for around 10-15% of dementia diagnoses. The pathology is varied, depending on which areas of the brain and blood vessels are

affected. The subtype of multi-infarct dementia is associated with a succession of minor strokes, causing localised damage, which is often detectable on scanning. One of the priorities here is to treat the underlying cardio-vascular condition.

There is of course no reason why cerebral atrophy cannot be caused by a combination of Alzheimer's and cardiovascular disease. Although 'mixed' type dementia is thought to account for 10-15% of dementia diagnoses, there is real difficulty in determining the extent of the relative contributions of the different forms of pathology. The relevance of this point to this study is that in people with a diagnosis of probable Alzheimer's disease the possibility of some other co-morbid pathology influencing the way their cognitive deficits are expressed cannot be completely excluded.

The strength of neuropathologically determined explanations of Alzheimer's disease lies in the research they have generated in the neurochemical changes seen in dementia. In Alzheimer's disease there is a reduction in noradrenergic, serotonergic and cholinergic neurotransmitter activity (Morris, 1999). Of particular interest is the depletion in cholinergic activity associated with memory and attentional impairment. This has given rise to drug treatments (acetylcholinesterase-inhibitors), which have been shown to have modest effects in slowing cognitive decline (Emre & Hanagasi, 2000).

Until recently, there was a general consensus that the disease model adequately explained the phenomenon of Alzheimer's disease. Yet although the disease model attributes the process of decline in dementia to neuropathological changes, the process that sets this neuropathology in motion in Alzheimer's disease has not been determined. Despite thirty years of investigation:

"Clinico-pathologic correlations have been so weak or entirely lacking that determination of proximate, let alone the ultimate, cause of Alzheimer's disease has not been possible." (Terry, 1992, cited in Kitwood, 1996, p.269).

Criticism of the disease model points to the empirically weak correlation between both the observed symptoms and the progression of the illness, and the extent of neurological damage subsequently observed at post mortem. Substantial neuropathology has been observed in autopsies of patients who were not thought to be demented. Similarly, there have been situations where the brains of people with a diagnosis of probable Alzheimer's disease have shown no significant neuropathology at post mortem (McKhann *et al.*, 1984).

Kitwood (1996) pointed out that some people deteriorate in functioning much faster than can be attributed to a progressive degeneration of the nervous system. Decline according to the disease model is a process expected to take years. Yet movement from moderate to severe dementia may occur in a matter of months, often following significant social or environmental changes such as hospitalisation or institutionalisation.

Furthermore cases of arrest in deterioration and even partial recovery (rementia) have been reported. Sixsmith, Stilwell and Copeland (1993) found that appropriate care interventions can create an environment where some individuals can regain lost cognitive and functional abilities. Such findings are not predicted by the medical model and have refocused attention on the quality of the care environment as a crucial factor in the dementing process.

The medical model describes the losses involved in dementia in terms of cognitive impairments that will lead to an inevitable decline in the person's sense of agency, or loss of self (Cohen & Eisdorfer, 1986). The consequence of this approach is to

view the person with dementia as unable to contribute to understanding the illness and its course. It has therefore been argued that the medical model disempowers people with dementia as non-persons who become a burden to their relatives or carers. This promotes a focus on the carer as the real person in need (Cotrell & Schulz, 1993). Whilst acknowledging the importance of providing appropriate support for carers, Cheston and Bender (1999a) argue that an over-reliance on the medical model has limited the sorts of care available to people with dementia.

1.1.3. The Dialectical Model

These findings led Kitwood (1993, 1996, 1997) to conclude that the medical model of dementia, or 'standard paradigm', is deficient on both conceptual and empirical grounds. He proposed a model of dementia based on a dialectical interaction between social psychological factors surrounding the individual and their internal cognitive decline. Within this model neurological impairment sets the limits to the data processing capacity of the nervous system. However, the manifestation and progression of Alzheimer's disease depends on the interplay between neurological impairment, personality, biography, physical health, and social psychology. These components of the model are described as follows.

Personality acts as a resource for action, in that it provides a repertoire of behaviour acquired through experience. Apparent changes in personality in dementia may be understood as the loss of resources, enhancement of some traits and the stripping away of some of the psychological defences.

Biography in this model is related to personality. A person's childhood, family, occupation, interests, great adventures and losses will impact on self-efficacy and self-esteem. Loss in later life may include multiple bereavements and changes in health, mobility, economic power as well as loss of cognitive functioning.

"We cannot understand a person in later life unless we have some sense of his or her story" (Kitwood, 1996, p.272).

Dementia is embedded in the general physical health picture of the individual. It is therefore important to think beyond psychological causation and to consider to what extent the person's difficulties may be attributed to some underlying physical health problem. A person's confused state may be due to a build up of toxins as a consequence of infections, kidney failure, drugs, hormonal imbalance and vitamin deficiency. Social withdrawal is often attributed to an inability to participate due to cognitive impairment, but may also be a consequence of loss of mobility, sight and hearing.

Social psychology in Kitwood's model refers to the social interactions whereby the person as a creative agent seeks to define situations, make sense of what others are doing and acts in the context of meaning. Certain interactions promote either the destruction or the maintenance of personhood. This is not just relevant to dementia; 'malignant social psychology' that undermines a person's self-esteem can be detrimental to anyone's psychological well-being. However, in the non-cognitively impaired person 'inner-stabilisers', such as defences against anxiety and rational understandings, will to an extent counteract the effects of malignant social psychology. Weak 'inner-stabilisers' make the person with dementia extremely susceptible to the impact of social psychological processes.

Neurological impairment, personality and biography are less open to manipulation than physical health and social psychology. The symptomatic presentation of dementia arises from a complex interaction of all five factors. However, the progression of the illness depends primarily on the interplay between neurological impairment and social psychology. For example, if a person's forgetfulness leads to

criticism, ridicule or shame, this might undermine self-esteem and lead to loss of social roles and a reduction in the person's involvement with the world around her.

Over the last decade or so, Kitwood's conceptualisation of dementia in terms of a dialectical relationship between the individual and her social context has greatly influenced research in the field. The way in which the losses involved in dementia are described in the literature has shifted from a focus on cognitive impairment to a loss occurring in both personal and social contexts (Cheston & Bender, 1999a). The strength of the model lies in its description of how interactions with others will influence the way a person responds to the onset and progression of dementia.

The model could, perhaps, be further enhanced by greater consideration of individual psychological processes that affect adjustment. A psychological understanding of dementia needs to consider how people cope with changes resulting from dementia. A consideration of the theoretical contributions in health psychology on coping with chronic illness may inform our understanding of coping with dementia.

1.2. COPING WITH CHRONIC ILLNESS

Any serious chronic or terminal illness places major psychological stress on the individual. Psychological stress is a particular relationship between the person and the environment that is appraised by the person as demanding and endangering her well-being (Lazarus & Folkman, 1984). Higher levels of stress and lower levels of well-being are generally reported in both the initial and end stages of chronic illness (Cassileth *et al.*, 1984). A person's adaptation must therefore be examined in relation to the specific time point in the individual's disease history; this study focuses on early-stage Alzheimer's disease.

1.2.1. Illness representations

The person experiencing the early-stages of cognitive decline may already hold her own representations of what it means to have dementia or Alzheimer's disease. Lay illness representations of dementia are often based on negative images of severe confusion, disorientation, incontinence, wandering and the need to be 'put away' into residential care. These images may stem from the person's experience of relatives with dementia, an experience which often evokes fears that this may one day also happen to them. The media also plays a part in presenting images of severe disability and carer strain in Alzheimer's disease. A recent example of this is the film *Iris*, which portrayed the life of Iris Murdoch. The effect of stigmatising illness representations is likely to be that of encouraging the person to hide her difficulties, often by way of social withdrawal. However other media reports about medical treatments may add a degree of hope to lay representations of Alzheimer's disease.

Coping with the threat of illness will invariably be dependant on the individual's beliefs about their illness based on their objective experience and subjective emotional responses. The Illness Representation Model (Leventhal, Nerenz & Steele, 1984) proposes that people are active problem-solvers who build up a picture of their illness and what they need to do to cope with it, and then evaluate their efforts at coping. The structure of illness representations provides a framework for understanding individual differences in adjustment and may have some relevance to the early-stages of Alzheimer's disease. The model proposes five attributes of illness representations:

1. Identity: beliefs about the identity of the illness based on symptoms and labels (e.g. "I'm forgetful")
2. Cause: perceived causes including internal and external attributions (e.g. dementia, ageing)

3. Consequences: perceived physical, social, economic and emotional consequences of the illness (e.g. disability, social isolation, death)
4. Time-line: the perceived time frame for the development and duration of the illness (e.g. progressive deterioration)
5. Controllability: the extent to which the illness can be controlled by the individual's actions or an external agent (e.g. covering up, compensatory strategies, medication).

Williams (1997) extended this model, understanding a person's reactions to their illness as an interaction between illness representation and self-schema. This places the person's experience of illness in the context of how they think about themselves (e.g. vulnerability, competency, worthiness, dependency), others (e.g. trustworthiness, dependability) and the perceived dangerousness of the world.

The Illness Constellation Model (Morse & Johnson, 1991) proposes four stages in the psychological development of an illness representation: uncertainty, disruption, a striving for the recovery of self and a restoration of well-being. In the uncertain stage the person attempts to understand the meaning and severity of the first symptoms. Disruption occurs when it becomes obvious that the individual is affected by a serious illness. This is experienced as a crisis characterised by intense levels of stress and an increased dependence on professionals and relatives. In striving for recovery of the self, the person tries to gain control over the illness using resources available in their environment and various forms of coping behaviour. With restoration of well-being, the person attains a new equilibrium within her environment, accepting the illness and its consequences. The model perhaps fails to acknowledge that a person's acceptance of her illness may be more of a matter of lack of choice, which may not be experienced as well-being. A further critique of this model is that adaptation to chronic illness is presented as a linear stage process.

Certainly with dementia (and other progressive diseases) this process will be cyclical, as the person is re-challenged with further disability.

1.2.2. The Transactional Process Model

Descriptions of adaptation processes in chronic illness often rely on stress-coping models. In the Lazarus and Folkman (1984) Transactional Process Model, coping is seen as a process by which the person manages the demands and emotions generated by a relationship with the environment that is appraised as stressful. When assessing a situation a primary appraisal is initially made of its potential significance for well-being. This involves an examination of what is at stake. Next a secondary appraisal is made, evaluating the options and responses available to deal with the situation. The process of appraisal is ongoing as the stressor is re-evaluated as more information is obtained. These cognitive appraisals are key determinants of which particular coping strategies are employed. A particular strength of the model is that it describes a process where strategies change over time according to the shifting context of the stressor (Lazarus, 1993).

Coping refers to a person's cognitive and behavioural efforts to manage demands. Lazarus and Folkman identified two coping functions: problem-focused and emotion-focused coping. Problem-focused coping involves the active management of the situation. Here the person attempts to alter the stressful situation by seeking information, taking direct action and planned problem solving. Emotion-focused coping involves the regulation of reactions to the event, by avoidance, denial, wishful thinking and positive re-appraisal. People with a greater sense of personal control are more likely to use problem-focused forms of coping. Where control is perceived to be external, people are more likely to engage in emotion-focused coping, particularly through denial and escape or avoidance.

Kiyak (1988) applied the Transactional Process Model to a longitudinal study in 57 persons with Alzheimer's disease and their carers (primarily spouses). Respondents were interviewed on how they coped with life events, including the changes they experienced due to Alzheimer's disease. A 34-item questionnaire was then administered, based on Pearlin and Schooler (1978) and Lazarus and Folkman (1984). The four dimensions of the questionnaire were: problem-focused coping, emotion-focused coping, acceptance and hopefulness. The interviews and questionnaires were repeated two years later, although at this stage only 19 of the original respondents were still alive and cognitively able enough to participate.

The primary mode of coping was found to be acceptance, which was represented in the questionnaire by such items as "*accepted the situation*", "*made the best of it*" and "*refused to let it get to you*". Acceptance items were endorsed by both patients and caregivers more frequently than any other coping mode at both baseline and follow up. At baseline the persons with Alzheimer's disease endorsed 75% of the acceptance items. Such items as "*becoming angry*", "*bitter*" and "*resentful*" represented emotion-focused coping. Both patients and caregivers endorsed 50% of the emotion-focused items at baseline. Problem-focused and hopefulness items were endorsed infrequently.

At two year follow up patients' endorsement of acceptance items had remained stable at 74%. Emotion-focused items had decreased to 15%. Kiyak concludes that there was a loss of active coping responses such as problem solving, information seeking and expressing emotions. Over time people with dementia become more passive in their choice of coping responses. Kiyak explains that widespread acceptance is not surprising given the chronic and irreversible nature of Alzheimer's disease. As such, acceptance is identified as an effective form of functional coping with cognitive decline. A particular limitation of this type of research is that it can

only quantify those aspects of coping that are predetermined by categories of the model. Nevertheless this study is one of the few published applications of the Transactional Process Model to coping with Alzheimer's disease in the literature.

The Transactional Process Model proposes that adaptation to chronic illness is largely dependent on the individual's ability to evaluate the stressor and her coping resources. It therefore tends to ignore the influence of the person's previous experience, their values and the availability of social support on coping behaviour.

1.2.3. Adaptive coping

Generally speaking problem-focused coping is seen as adaptive for controllable events and emotion-focused coping for uncontrollable events. Lazarus (1993) points out that there is no straightforward relationship between problem-solving and adaptive coping. On the contrary, in certain situations where the person has no control, attempts at problem-solving are likely to be counterproductive and lead to distress as the person's efforts fail. This suggests that a person's values (e.g. achievement orientation) may compel some people to adopt coping styles that are maladaptive.

Furthermore, the social values of the investigator may colour the manner in which research findings are presented. Consider the use of language in the following extract from Feifel, Strack and Nagy (1987, p.622):

"Raging against the dying of the light is a characteristic of life-threatened patients who view their illness as perilous and who are outgoing and open to life...Patients who find themselves on the lower rung of the socio-economic ladder...prefer avoidance as a coping tactic...Included in this constellation are also patients who have little inclination to engage in life with vitality and gusto...Acceptance-resignation as a coping strategy strongly mirrors both a limited power to influence the course of one's illness and a lack of hope."

The authors create an image of *good* coping versus *bad* coping, polarised according to the value they attach to the participants' socio-economic and personality characteristics.

Zeidner and Endler (1996) identify adaptive coping strategies in terms of their efficacy within a problem/emotion focused and dys/functional matrix (Table 1). The aim of problem-focused strategies is to alter the stressful situation. Here functional problem-focused coping strategies include seeking accurate information about the problem, developing a realistic action plan and seeking social support in terms of dependable advice and help. By contrast, dysfunctional problem-focused coping strategies seek to find solutions through inaccurate information and questionable advice, developing unrealistic plans (e.g. winning the lottery) and seeking support from inappropriate sources.

Table 1 Matrix of problem/emotion focused and dys/functional coping strategies.

Type	Aim	Functional	Dysfunctional
Problem-focused	Problem solving	<ul style="list-style-type: none"> - Seeking accurate information - Seeking dependable help - Developing a realistic action plan - Following through on the plan 	<ul style="list-style-type: none"> - Seeking inaccurate information - Seeking questionable advice - Developing unrealistic plans - Not following through on plans
Emotion-focused	Mood regulation	<ul style="list-style-type: none"> - Making and maintaining socially supportive relationships - Catharsis and emotional processing - Reframing and cognitive restructuring - Relaxation routines - Physical exercise 	<ul style="list-style-type: none"> - Making and maintaining destructive relationships - Avoidance of the problem - Unproductive wishful thinking - Drug and alcohol abuse - Aggression

Source: Based on Zeidner and Endler (1996) in Carr (1999) pp 43.

Where stressors are uncontrollable, functional emotion-focused coping strategies include making and maintaining socially supportive and empathic friendships. The ability to use social support, where it is possible to confide deeply felt emotions and beliefs, is largely dependent on the person's internal working model of relationships based on secure attachment and a capacity to empathise with others. Social support performs a crucial role in allowing the person to make use of catharsis as a coping strategy to emotionally process stressors. Reframing and cognitive restructuring are

functional emotion-focused strategies that allow the person to think about their situation in a different way. Distraction, relaxation and exercise are other functional emotion-focused strategies that help the person to regulate negative mood states that arise from stress. By contrast denial and wishful thinking are described as aspects of dysfunctional emotion-focused coping strategies.

The matrix gives a useful overview of coping strategies, however it cannot be assumed that adaptive and maladaptive coping are objective value-free labels. It would seem unlikely that a person would actively seek inaccurate information and questionable advice; the appropriateness of support will be a value judgement. Whether or not a strategy is functional will be dependent on context. Whereas the matrix classifies denial as dysfunctional, it could be argued that for some people in certain contexts it may be functional. Bearing such criticisms in mind, the relevance of this matrix for people with early-stage cognitive impairment lies in focussing support to facilitate functional problem solving and mood regulation.

1.2.4. A revised structural model of coping with chronic illness

In reviewing various stress-coping models Maes, Leventhal, and de Ridder (1996) point out that it is impossible to fully appreciate the impact of a chronic disease without considering its interaction with the individual's social environment, life goals and values. From this they present a comprehensive model of coping with chronic illness as presented in Figure 1.

Within this model, disease and demographic characteristics, as well as life events, contribute to the appraisal of disease-related events. The most stressful life events for older people according to one study (Reich, Zautra & Gurnaccia, 1989) are serious illness or the death of a loved one. These events are likely to significantly

impact on a person's identity and social roles. It may also be useful to consider the challenges of changes in social roles such as retirement or becoming a grandparent.

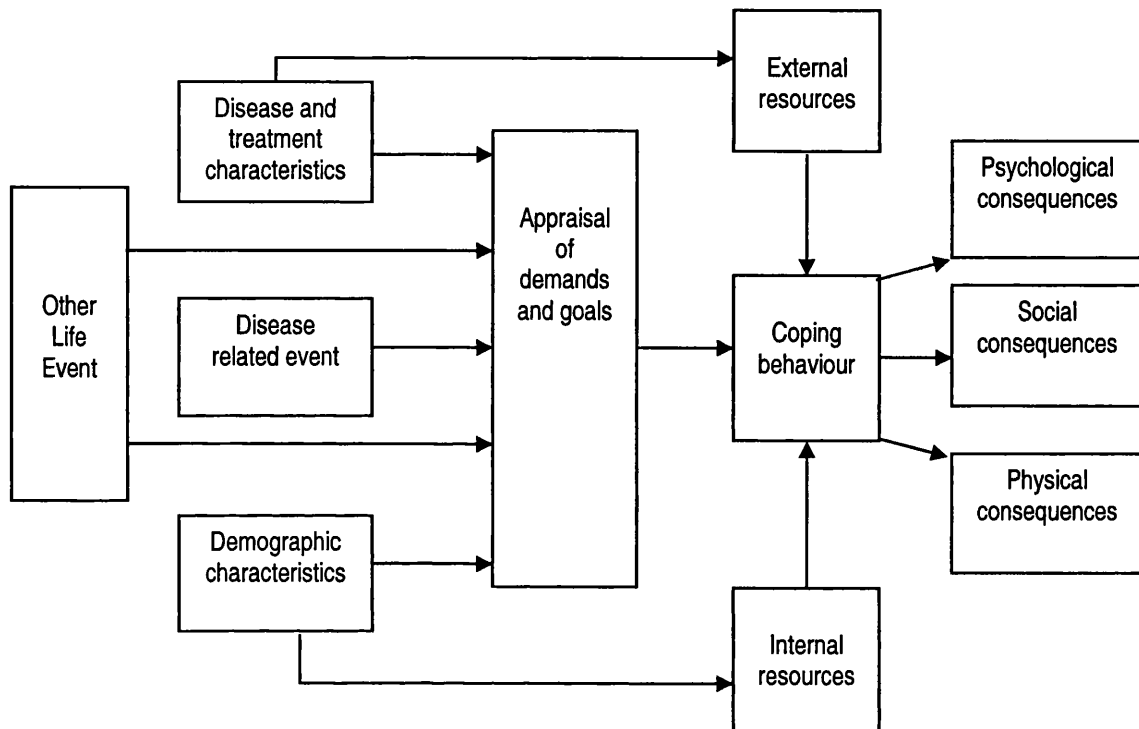


Figure 1. A model of coping with chronic disease (Maes *et al.*, 1996)

In terms of disease and treatment characteristics, Perroz and Reicherts (1992) point to several dimensions that influence appraisal and coping in chronic disease: valence (the inherent stressfulness of a situation); controllability (the inherent opportunities for control within a situation); changeability (the probability that a situation will change by itself); ambiguity (the degree to which insufficient information distorts the meaning of a situation); and recurrence (the inherent likelihood of the stressful situation happening again). Maes *et al.* (1996) review the literature to examine how these dimensions relate to coping responses in various chronic illnesses. A positive relationship has been found between valence and avoidant or passive coping. Low controllability is associated with avoidant, emotion-focused coping, whereas high controllability is associated with active problem-focused coping. Confrontative problem-oriented coping has been found to be associated with

the degree of changeability in chronic disease. Passive forms of emotion-focused coping appear to be associated with ambiguity and recurrence. The extent to which these dimensions relate to early-stage Alzheimer's disease will depend upon the quality of professional and social support. The potential is there for the person to experience her difficulties in terms of high valence, low controllability, low changeability, high ambiguity and high recurrence, which are associated with passive emotion-focused avoidant coping strategies.

Demographic characteristics such as age, gender, race and social class have been found to contribute to the interpretation of chronic illness and thus influence coping. Stress-coping models assume that there are socially-shared illness representations and expectations about mal/adaptive coping, which may vary between social groups, including age cohorts. Dementia mainly affects older people, who are often subjected to ageism and negatively stereotyped as being asexual, slow, frail, moralistic and out of touch with rapid changes in society and technology. These negative images of older people are often internalised and accepted as correct by many older people (Cheston & Bender, 1999a).

Of particular interest to this study is the finding by de Ridder and Schreurs (1996) that a person's social position will affect her appraisal and coping with illness. Female, lower educated and older chronic patients tend to use more avoidant and emotion focused coping. Social values position a person in society and will impact on her ability to effect change. Older women are likely to have been socialised into more traditional social roles, but will have lived through a period of enormous change in the roles and opportunities available to women. The extent to which women have had the opportunity to develop and maintain a variety of social roles may be relevant to coping processes. The view expressed by Lazarus (1993) that Western society values problem-focused coping is interesting considering that this

approach is more associated with male coping styles, higher socio-economic status and education.

Within Maes' model external resources refer to money, time, distance from professional help and the social support upon which the person relies. The relationship between social support and adaptation to chronic illness, as well as between social support and disease progression, may be particularly relevant to dementia. Both self-efficacy and control depend in part on the feedback received from others. Social relationships that provide a sense of being loved and valued have a protective function that increases self-efficacy, self-esteem and sense of control. Manne and Zautra (1989) found that in women with rheumatoid arthritis, those with less supportive husbands were more inclined to use wishful thinking, whereas those with supportive husbands used more problem-solving coping. In couples coping with chronic illness Coyne and Fiske (1992) found a dual relationship between the coping of the patient and that of the carer. For most people with Alzheimer's disease the carer is a close relative who will be making his or her own appraisal of their family member's illness and adopt coping styles that can facilitate adapting to living with a person with dementia. In such close relationships there is likely to be a history and repertoire of coping responses for dealing with adversity that will influence reactions to the current challenge.

Internal resources in the model refer to the person's energy, physical strength and personality characteristics. According to Friedman and di Matteo (1984), there is a positive relationship between intelligence and information seeking, and between ego-strength and more active adaptive coping. Optimists seem to cope in more active, problem-orientated ways, whereas pessimists appear to employ more passive, avoidant styles. The relationship between the constructs of optimism and depression highlights possible mood considerations in relation to the person's

coping. In relation to dementia, it is important to consider the impact of neurological impairment on the person's internal resources.

The particular strength of the structural model presented in Figure 1 is the way it attempts to demonstrate the relationships between the complex factors involved in appraisal and coping with chronic disease. However, if we consider coping as a process, the model in Figure 1 may be modified with the consequences of coping behaviour feeding back into the appraisal of demands and goals.

Structural models as presented by Lazarus and Folkman (1984), and Maes *et al.* (1996) fail to distinguish between coping actions (actual ways to deal with the problem) and coping functions (the goals these actions intend to achieve). Ferguson and Cox (1997) provide a functional account of coping and suggest that coping behaviours may be understood in relation to four functions: emotional regulation (dealing with the emotional consequences of the situation); approach (confronting the problem); reappraisal (attempts to reframe the meaning of the situation); and avoidance (attempts to ignore the situation). Both functional and structural accounts of coping are necessary, but most research has focussed on structural models.

Krohne (1993) presents a hierarchical model where the function of coping is represented at the highest level, whilst coping strategies occur at an intermediate level and specific coping acts and responses at the lowest level. The function of coping for the person with dementia is to re-affirm their existence and in some cases redefine their lives. This has been referred to as maintaining a sense of self (Clare, 2002a; Gillies, 2000; Harris & Sterin, 1999; Pearce, Clare & Pistrang, 2002).

1.3. SELF AND IDENTITY IN CHRONIC ILLNESS

To understand the experience of chronic illness, it is essential to study what ill people think, feel, and do in their natural settings. Qualitative research in this field emerged in response to analyses that failed to account adequately for patients' actions. Charmaz (2000) describes how people experience becoming and being ill, and points out that culture shapes the meanings people attribute to their illness. In a review of the research she notes similarities in themes that emerge in different studies: ambiguity and uncertainty, autonomy and control, stigma and shame, isolation and connection, and loss and reconstruction of self.

In one of her earlier studies, Charmaz (1983) described the process of a loss of self in interviews with chronically ill patients with various diagnoses. Former self-images appeared to crumble away without the simultaneous development of equally valued new ones. As a result of their illnesses, participants led restricted lives, experienced social isolation, felt discredited and suffered guilt about burdening others.

Illness poses identity problems. It disrupts a person's plans and alters lives. Identity here refers to attributes, actions and appraisals of the self. Preferred identities are those we choose ourselves, reflecting our hopes, desires and plans for the future. Charmaz (1987) found that over time ill people choose different types of preferred identity, reflecting the difficulties that illness imposes on their ability to realise their aspirations and life goals. Social definitions of illness in terms of stigma will shape a person's response to their diagnosis. Thus according to Charmaz, the struggle of many chronically ill people to realise a preferred identity is motivated by their wish to avoid or minimise stigma. For some this may involve aiming for high-level identities to overcome stigma. For others it entails a lower level identity that allows them to withdraw from the world in order to avoid stigma.

Charmaz conceptualises identity in illness as forming a hierarchy. The Supernormal Social Identity will try to compensate for difficulties in illness by demanding extraordinary achievement. The function of this identity is to reject a negative image of a chronic illness that is potentially stigmatising. The Restored Self Identity aims to reconstruct the previous identity prior to illness. It rests on the assumption by the person that she will recover from her illness. The Contingent Personal Identity is one that is hypothetically possible, but uncertain due to the illness. It is based on beliefs about the fragility of the person's hopes and aspirations in the face of illness. Finally the Salvaged Self is an identity based on some valued activity or attribute that the person is able to maintain despite illness. At this level people *"turn their attention to carving out a tolerable existence in their present circumstances"* (Charmaz, 1987, p.311).

Progressive illness often entails reducing one's goals and aiming for a lower level in the identity hierarchy. Whereas early in an illness a person may aim for a Supernormal Social Identity, as the person becomes more and more impaired the main objective may simply become that of maintaining self-respect in the face of physical deterioration. Charmaz (1987) concludes: *"The struggles of chronically ill people to maintain or create valued selves reflect a strength and vitality seldom ascribed to them"* (p.319).

In her study of men diagnosed with chronic illness, Charmaz (1994) used grounded theory to identify four major processes in their experience. There was an awakening to death after a life-threatening crisis. The men then attempted to accommodate to uncertainty after the realisation that the crisis had lasting consequences. This led them to define their illness and disability. They then strove to preserve the self to maintain a sense of coherence while experiencing loss and change. However, adapting seldom occurs at only one time point. Rather,

chronically ill people are forced to adapt continually as they experience new losses (Charmaz, 1995).

By examining self-identity in chronic illness, Charmaz provides a framework that allows us to understand coping behaviours in terms of the person's goal in achieving a preferred identity. This may be relevant in understanding different coping responses between individuals in terms of their goals and within individuals over time as their changing circumstances put them in a position that requires them to re-evaluate their goals. In qualitative research in Alzheimer's disease this approach has influenced the interpretation of coping responses as a process of holding on to a preferred identity until the person is confronted with their limitations and reconstructs their sense of self by adapting their expectations and roles (Clare, 2002a; Pearce *et al.*, 2002). Perhaps a neglected area in this field is an examination of gender differences in people's attempts to maintain a preferred identity.

1.4. THE IMPACT OF DEMENTIA ON SELF

It may be useful to consider what is meant by loss of self in dementia by looking at how the self is conceptualised. In part, the self can be seen as a memory structure. Indeed the idea of memory being central to the self can be traced back to early psychological writings of the nineteenth century:

"The phenomenon of the Self and that of Memory are merely two sides of the same fact" (Mill, 1869, p.174).

The self is thus credited with the ability to retrieve knowledge of events and of the past and to maintain a coherence of personal experience. Personal memories act as a point of reference, which maintains continuity in our experience, or personality. It is from this perspective that the impact of dementia has been described as a gradual loss of self (Cohen & Eisdorfer, 1986; O'Connor, 1993).

Whilst acknowledging the effect of memory impairment, more recent accounts of the impact of dementia point out that some elements of self can be retained. Kitwood (1997) focused on the parts of the self that are beyond memory. He used the concept of personhood, which is associated in social psychology with such constructs as self-esteem, the place of the individual within a social group, the performance of given social roles and the integrity, continuity and stability of a sense of self. People gain a sense of who they are through social interaction. Thus, according to Kitwood, personhood is a status that is *“bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust”* (Kitwood, 1997, p.8). As discussed above, Kitwood described how social care practices can interact with the process of neurological change to weaken (or indeed strengthen) personhood. Aspects of a malignant social psychology include negative interactions such as: treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, invalidation, banishment and objectification (Kitwood, 1993). A primary goal of person-centred dementia care is to help the person to retain a sense of personal identity and integrity.

Similarly, a social constructionist account of loss of self looks at how people with dementia can be deprived of their social selves (Sabat & Harré, 1992; Sabat, 1994). People change their expectations of a person with dementia and will act differently around her. This forces the person into a role with lowered expectations, creating a self-fulfilling prophecy. The person with dementia is described as creating new roles and adapting old ones to cope with the onset of dementia (Sabat, 1994). As she develops a new social self she invites others to join in its construction. However, often those close to the person with dementia refuse to take up complementary roles, and undermine the process.

Sabat (2001) gives an account of the effect of dementia on three aspects of self. Self-1, associated with a sense of personal singularity, remains intact and is expressed in the person's discourses, specifically through her use of the first person pronoun. Self-2 refers to the totality of self-attributes a person has. A person retains a host of attributes and beliefs about those attributes, some of which are highly valued. A diagnosis of Alzheimer's disease will cause a decline in the person's formerly healthy, valued attributes and will act as a source of embarrassment, humiliation and sadness. Self-3 refers to aspects of the self that are presented socially and publicly. Here losses are indirect rather than a direct result of the disease. These losses are related to the ways in which the healthy others position and treat the person with dementia. The way others react to the selves that are presented can impact on the person's self-concept.

Harris and Sterin (1999) examined the concept of self and personal identity in early-stage Alzheimer's disease. A major theme was the changing sense of self. According to the authors the self is not lost in Alzheimer's disease, but the sense of "who one is" is often in a state of flux. Participants grieved for losses that affected their personal identities, which included the loss of meaningful roles, independence, self-worth and respect, sense of competency, memory, and relationships. Three core values were identified that helped define personal identity: meaningful productivity, autonomy and a need for comfort and security. These values were discussed as important for developing an environment that affirms self-identity for the person with dementia. The social aspect of loss of self was apparent in the participants' acute awareness of the reaction of others.

1.5. AWARENESS, DEPRESSION AND ANXIETY

Woods and Britton (1985) have pointed out that in dementia research the importance of the person's emotional reactions to her difficulties has often been

overlooked. They hypothesised that persons with dementia may function below their actual capabilities in order to avoid their fear of failure. Such actions in themselves are based on an awareness of their difficulties. Yet apparent unawareness of deficits is a challenging problem frequently encountered in individuals with Alzheimer's disease (Cotrell, 1997). This is a complex issue as it is hard to distinguish to what extent apparent unawareness can be attributed to neurological impairment, avoidance or denial.

Cotrell and Lein (1993) conducted interviews with five spouses of people with Alzheimer's disease. The interviews focused on the person's awareness that they had Alzheimer's disease. Three were male and two female. None of the spouses considered the person with Alzheimer's disease to have an accurate awareness of the level of their cognitive impairment. A more realistic perception of the disease correlated with increased severity of depressive symptoms. When confronted with deficits, they tended to react strongly: blaming others, withdrawing from social contact and denying their difficulties. Such responses appeared to be consistent with their premorbid stress-coping styles. Recurrent issues for the person with Alzheimer's disease were concerns about their spouse's infidelity and financial security. These were interpreted as reactions to an underlying sense of loss. An important criticism of this study is that it relied on the spouses' accounts and did not directly include the views of the persons with Alzheimer's disease. Thus the view that none of them had an accurate awareness of their level of cognitive impairment assumes that the carers' perceptions were accurate. It is possible that a range of factors could influence the carers' accounts of their spouses' awareness of cognitive impairment.

Psychodynamically informed studies introduce notions of defence mechanisms in coping responses. The person with dementia is seen to repress her awareness of

an encroaching intellectual decline. This may be observed in her withdrawal from activities or the blaming of others. These protective strategies may be useful in the early-stages of dementia, preventing her from being overwhelmed by feelings of loss and threat, but in later stages they fail and lead to a catastrophic reaction (Balfour, 1995; O'Connor, 1993). Bahro, Silber and Sunderland (1995) reported case studies of seven people with mild to moderate Alzheimer's disease. A variety of defences in coping with the threatening aspects of the onset of Alzheimer's disease were reported, including partial or complete denial, dissociation of affect, vagueness, and circumstantiality. However, the authors observed that it was difficult to differentiate between organic deficits and psychological defences (i.e. questioning whether the denial is part of the dementia or a defence mechanism). These case studies relied on the researcher's observation of the participants' behaviour, which will have been influenced by the fact that they were hospital patients undergoing assessment. Again, this study did not include the perspective of people with dementia.

In early-stage dementia an awareness of such loss may lead to several psychological responses, including anxiety and depression. Depression is the most commonly reported affective response in dementia. In their review of the literature Cheston and Bender (1999b) found that reported rates of depression in Alzheimer's disease varied from 12-24% to 87%. The relationship between depression and dementia is complex. Depression itself may be a risk factor for dementia, or may exacerbate cognitive decline in dementia. Certainly the behavioural aspects of depression, such as withdrawal from the world, may be seen as a coping response that serves to protect the individual from failure.

Awareness of a declining mental capacity and of the reactions of others is likely to create considerable anxiety. Dementia is possibly one of the greatest fears in ageing. Even when it is diagnosed, uncertainty remains about the rate and severity

of the decline. A behavioural response to such uncertainty may be an unwillingness to explore the environment. Some awareness of cognitive decline and changes in the marital relationship may evoke fears of abandonment. This insecurity has been interpreted in terms of attachment theory (Miesen, 1992). In later stages of dementia confusion about whether parents are still alive has been interpreted as an expression of fear and a need for security. The person with dementia thus experiences a gradual loss of security, together with an inability to form new attachments.

People may use a range of psychological strategies in their attempt to regain control over the threat to their sense of self. When the publicly presented self is based on the person's need to manage perceptions of social stigma, others may interpret this as unawareness (Clare, 2002b). In a qualitative study of twelve people with early-stage Alzheimer's disease, Clare (in press) found that all the participants acknowledged that they had memory problems, but their appraisal of this varied and included attempts to normalise, minimise or confront the difficulties. The range of responses is conceptualised as being on continuum running from maintaining continuity with a prior sense of self to a reappraisal or adjustment of the sense of self to the difficulties.

1.6. MODELS OF COPING WITH DEMENTIA

1.6.1. Stages of coping models

Keady and Nolan (1995) present a model of coping in dementia that proposes nine stages: slipping, suspecting, covering-up, revealing, confirming, maximising, disorganisation, decline and death. The person with dementia notices that she is having difficulties, but as an active agent she initially attempts to cover up slips from other people. Gradually she either decides or is forced to share her concerns with others, including professionals who confirm the problem by reaching a diagnosis.

Acknowledging her difficulties, she attempts to maximise her abilities using a variety of coping strategies. However, increasing neuropathology and social adversity eventually lead to disorganisation, decline and death.

Dementia is thus experienced as loss, which triggers a process of grieving, often conceptualised as occurring in stages of concern, denial, anger, depression, acceptance and reconstruction. Cognitive deficits may interfere with the person's ability to progress through the stages of grieving. According to Solomon and Szwabko (1992) the person with dementia may be unable to move to the final stages and may get stuck in the stage of disorganisation. Stage models can be useful conceptual tools. However, a common criticism of such models is that not everyone will necessarily proceed through the stages in a fixed order. Stage models ignore the personal histories and values of people with dementia and therefore do not acknowledge that individuals with dementia will be experiencing their losses in different ways.

1.6.2. The Adaptation Coping Model

Dröes (1997) presented a model for adaptive coping with dementia based on the crisis model of Moos (1984) and the coping theory of Lazarus and Folkman (1984). In this model, personal, illness related, material and social factors influence cognitive appraisal (the meaning a person ascribes to cognitive impairment). It provides a framework for interventions for challenging behaviour, which are partly explained as inadequate ways of coping with stress caused by difficulties with a number of adaptive tasks in relation to dementia. These include: dealing with disability; preserving an emotional balance; maintaining a positive self-image; preparing for an uncertain future; and developing and maintaining social relationships. With regard to nursing homes additional adaptive tasks include dealing with the nursing home environment and treatment procedures, and

developing an adequate relationship with professional staff. The demands of these adaptive tasks will evoke stress and emotional responses, such as anxiety, grief, shame and anger.

The person strives to maintain a balance between the demands of the adaptive tasks and her existing resources. Effective coping maintains or restores the balance. Ineffective coping with the stress generated by a particular adaptive task will precipitate a crisis. In crisis, the person is off balance and no longer in control of her situation. This can be recognised by the relatively sudden occurrence of behavioural symptoms, as well as depression, acute anxiety, panic attacks and physiological disorders. Inadequate coping may lead to an unstable balance. This is characterised by regular, temporary behavioural problems, which when observed over a period of time can be linked to specific situations that require particular adaptive tasks. This unstable balance threatens to collapse into a downward spiral of psychosocial problems (e.g. chronic behavioural and communication problems, and isolation).

The model has been used to formulate behavioural problems as a 'psychosocial diagnosis' that identifies which of these adaptive tasks the person with dementia has difficulty with. This guides an intervention based on reactivation, resocialisation and improving affective functioning. The 'psychosocial diagnosis' will also identify the support needs of the carer in terms of information, practical help, emotional support and increasing their social network. Dröes, Meiland, de Lange, Vernooij-Dassen and van Tilburg (2001) reported that an intervention based on the model significantly decreased problematic behaviour, in particular inactivity and unsocial behaviour. In a seven-month period, behavioural problems led to admission to residential care in 30% of the control group compared with 8% of the intervention group. This difference was attributed to higher levels of self-reported competence in the carers that participated in the intervention.

A particular strength of the model is the idea of the person striving to maintain equilibrium and the recognition that adaptive coping tasks can also be a problem for the carer. The model is however limited by its focus on challenging behaviour, which may be less evident in the early stages of cognitive impairment.

1.6.3. An interpersonal model

A review of the coping literature on dementia shows that much of the research has focused on coping in caregivers, although a small body of work has started to address coping in the person with dementia. Little attention as yet has been given to the inter-relationship between the two, although some models of coping with chronic illness (e.g. Maes *et al.*, 1996) make this relationship explicit. In their presentation of a framework for stress and coping in the families of Alzheimer's patients, DeLongis and O'Brien (1990) focused mainly on the carer's perspective. However, it is possible to consider aspects of their model from the perspective of the person with dementia.

DeLongis and O'Brien extended the Lazarus and Folkman cognitive model of stress and coping by pointing to a role for interpersonal factors in determining a number of aspects of coping in ageing families. Their discussion of the influence of social relationships on coping is equally valid for the person with dementia and the carer. Through the use of social referencing, people turn to others for a sense of what is considered appropriate coping in a given situation. The modelling of effective coping may be one reason why support groups are helpful.

The notion of relationship-focused coping (a form of coping directed at maintaining and regulating social relationships) is presented alongside emotion- and problem-focused coping, mainly with the carer in mind. It is suggested that empathic coping is one mode of relationship-focused coping that could enhance the well-being of

later-life families faced with the task of caring for a chronically ill family member. In empathic coping, the carer attempts to perceive accurately the affective world of the dementia sufferer and tries to communicate accurately and sensitively their understanding of this. The following quote originally described the challenge for the carer, yet it may also more poignantly describe the difficulties faced by the person with dementia in coping:

“Successful coping may depend not only on our ability to keep our emotions under control and our ability to resolve problems, but also on our ability to regulate our relationships with involved others” (DeLongis & O’Brien, 1990, p.229).

This interpersonal model of coping in carers therefore highlights the importance of affiliation as an important coping strategy for dealing with adversity, and this may be a particularly difficult strategy for a person with dementia to employ. Much will depend on the shared history of the person with Alzheimer’s disease and their relative (Coyne & Fiske, 1992).

1.7. QUALITATIVE RESEARCH

It can be argued that more exploratory research needs to be carried out to describe the coping processes of people with dementia. Questionnaire design studies such as that of Kiyak (1988) impose predetermined categories of coping, an approach that may neglect important aspects of the person’s experience. A number of qualitative studies have used small semi-structured interview designs analysed by Grounded Theory (Strauss & Corbin, 1990) or Interpretative Phenomenological Analysis (Smith, Jarman & Osborn, 1999) to investigate the subjective experience of early-stage dementia (Clare, 2002a; *in press*; Gillies, 2000; Harris & Sterin, 1999; Keady, Nolan & Gilliard, 1995; Pearce *et al.* 2002).

Looking at how individuals made sense of their illness, Gillies (2000) found that most of the participants appeared to be unaware of, or had forgotten their diagnosis

of dementia. They conceptualised their difficulties as a memory problem, accounted for by normal ageing. There was a tendency to minimise their difficulties by referring to others perceived to be worse off. According to Gillies, the main themes of minimisation and normalisation allowed participants to ignore the degenerative reality of the dementing process.

Various practical coping strategies were observed in all of the studies. Practical coping here referred to how the person manages the day-to-day challenges of failing memory. Gillies (2000) describes how participants kept notes about personal information at hand, used a diary for remembering appointments and posted notes around the house. Some participants commented on how such strategies can fail, for example one woman explained how a diary would be useful as long as she could remember to fill it in and look at it (Gillies, 2000). Other strategies, such as posting notes around the house, were instigated by carers. A major coping strategy was therefore an increasing reliance on carers for reassurance, guidance, clarification and as a proxy memory.

Multiple coping strategies by which participants attempted to maintain their sense of self and some control over their lives were also reported by Harris and Sterin (1999). Most effective and frequently used strategies included: maintaining a daily routine, making lists and keeping a diary, relying on support from family members, attending support groups and relying on their faith.

In various studies there appeared to be a tension between attempts to preserve skills and independence and covering up cognitive decline (Gillies, 2000; Harris & Sterin, 1999; Keady *et al.*, 1995). Some participants displayed a fighting stance, attempting self-reassurance by using positive coping statements and tried to preserve their abilities by way of memory exercises (Keady *et al.*, 1995). Several of

the studies found that participants attempted to maintain a sense of continuity and self-esteem by trying to engage in valued social roles and activities (Harris & Sterin, 1999; Keady *et al.*, 1995).

Yet there was also some acknowledgement that memory failure was humiliating and therefore needed to be disguised (Gillies, 2000). Perhaps this can be referred to as a second order normalisation: not only was forgetfulness perceived as a normal part of ageing, but it was also felt to be normal for a person to disguise this as much as possible. The use of humour was found to be an important social skill to deflect possible public humiliation in several studies (Harris & Sterin, 1999; Keady & Nolan, 1995; Pearce *et al.*, 2002)

Disguising the problem can be seen to be an emotional coping strategy, which according to Gillies can be interpreted as the person's acute awareness of their difficulties and their need to pass themselves off as normal. When confronted with their difficulties many participants denied there was anything wrong. Another strategy was to avoid challenging situations to reduce the chance of failure (Gillies, 2000). The unfortunate effect of such avoidance is inevitably to reduce the person's involvement in the world, which by way of lowered expectations will feed into a malignant social psychology as discussed earlier.

Difficulties maintaining autonomy and social roles could be experienced as distressing. Some participants expressed feelings of worthlessness in terms of letting loved ones down and becoming a burden (Gillies, 2000). However, the most common coping strategy found by Gillies was that of resignation: an acceptance of circumstances that were perceived to be beyond the person's control.

Harris and Sterin (1999) described a typology of five different reaction patterns. *"I'll live until I die"* was a reaction of fighters, who intended to take control of the disease and their lives as best they could. This approach preserved their sense of self as very independent persons. *"I accept what I have"* was an approach of those who acquiesced without much of a struggle. These people were to some extent relieved to give up some of their responsibilities without feeling guilty, accepting their diagnosis and adjusting their new lives to it. Those for whom Alzheimer's disease was too devastating and thus needed to be denied in order to maintain their sense of self invoked the view *"There is nothing wrong with me"*. Denial was often expressed as anger about others' treatment of them. *"I'm just struggling to get through the day"* was the reaction of those who felt overwhelmed by their daily struggles, and these people also often tried to hide their diagnosis. Finally, *"I'm giving up"* was the response of those who no longer felt able to continue their attempt to remain who they were.

Two of these studies included participants with various types of early-stage dementia including Alzheimer's disease, cardiovascular or an unclassified dementia (Gillies, 2000; Keady *et al.* 1995). This is problematic in that the participants' actual diagnosis may influence their appraisal of their difficulties. For example previous research suggests that people with vascular dementia have more insight into their difficulties than people with Alzheimer's disease (Gustafson & Nilsson, 1982; de Bettignies, Mahurin & Pirozzolo, 1990).

Whereas Gillies (2002) and Keady *et al.* (1995) collected data only from the person with dementia, more recent studies by Clare (2002a) and Pearce *et al.* (2002) triangulated the data collected from the person with dementia with data provided by their partners. A caregiver's account can validate the data collected from the person with dementia, provide clarification or give a contradictory perspective. It was

however recognised that the caregiver's account has its own biases. Both these studies show how people actively adapt to early-stage Alzheimer's disease and reconstruct a sense of self.

Clare (2002a) examined the coping strategies of nine men and three women with early-stage Alzheimer's disease using semi-structured interviews with the participants and their partners. The data was analysed by Interpretative Phenomenological Analysis. The coping processes are described as a tension between protective strategies to maintain the self-concept and a confrontation of the changes in order to integrate them within the self-concept. These coping responses are conceptualised as located on a continuum of self-maintaining to self-adjusting responding. Holding on to roles and abilities and compensating for deficits were the most commonly reported strategies, and may be seen as protective strategies to maintain a sense of self and normality. Fighting and coming to terms with loss of ability were seen to be attempts to integrate the changes within the self.

None of the above studies have controlled for possible gender differences and few provided information about participants' social backgrounds, which could theoretically be relevant to coping. Pearce *et al.* (2002) focused on men and described their coping and appraisal as a cyclical process of maintaining and reconstructing their sense of self. Twenty men with early-stage Alzheimer's disease were interviewed and the data analysed by Interpretative Phenomenological Analysis. Fourteen themes were identified, under two higher-order themes, similar to those in Clare's study: maintaining a sense of self and reappraising / reconstructing a sense of self. The men attempted to maintain their abilities, roles and sense of self, but if they became aware of their limitations they reappraised their situation and reconstructed their sense of self by adapting their expectations and roles. The study also examined how men's past occupations could influence appraisal and coping in

early-stage Alzheimer's disease. Although based on a relatively small sample, the study suggests that men with a semi-skilled working history were more likely to minimise their difficulties, whilst men with a professional-managerial background used more practical coping strategies. An interest in the effect of occupational background on coping in dementia was the main reason why Pearce *et al.* (2002) focused their research on men. However, having developed a model of how men attempt to cope and adjust, it is relevant to consider how appraisal and coping processes might differ for women with early-stage Alzheimer's disease. This is the focus of the present study.

1.8. SELF IDENTITY IN OLDER WOMEN AND DEMENTIA

1.8.1. Interpersonal values and women's sense of self

Women have been largely invisible in social scientific research. Where women have been studied, they have been found to be inferior to men in terms of moral development, intelligence and conversational style (Willig, 2001). The same may be said about coping, where problem solving is socially valued and identified with as a male coping style. Research in general assumes 'male' to be the norm. It has often been pointed out that most social and psychological research has been conducted with young, white, middle-class participants. This sets a standard against which wider society is measured.

Feminist researchers (Gilligan, 1982; Miller, 1976) point out that human development in psychological literature has until recently referred to male development. The primary developmental tasks for men have traditionally been those of separation, differentiation and autonomy. Thus Erikson (1968) describes the development a healthy identity in terms of having a sense of self apart from one's family. By contrast traditionally the expectation of women has been that they take care of the needs of others, first the men, then the children, then the elderly.

According to James (1985) women's worth is very much dependent on their roles as wives and mothers. This is perhaps more relevant to the cohort of women who grew up in the first half of the twentieth century, from which participants for this study are drawn. Women passed from their families of origin to their families of procreation, with no space in between to be independent (unlike men). The pressure on women in this cohort not to strive for independence was intense. They may have lowered their sights because of educational, social, internalised or family attitudes. Thus in relation to psychological interventions with older women Crose (1991) points out that therapists may be frustrated by a client's inability to act autonomously and assertively.

Miller (1976) proposed that theories of human development should recognise the different pattern of women's development based on a context of attachment and affiliation with others. Women's sense of self is thus described in terms of the ability to develop and maintain relationships. This makes them more likely to judge themselves in terms of their ability to care. They typically feel guilty when they 'fail' to do so. The relevance to this study is that a loss or disruption of relationship either through cognitive impairment, other incapacity related to ageing or widowhood is perceived as a loss of identity.

1.8.2. Widowhood

Older women's sense of self is centred in relation to others. Yet increasingly the very old tend to be widowed women, living alone. Elderly people living alone show more symptoms of depression, especially if this is related to the loss of a partner (Brody, Denninger & Trotman, 2002). Social isolation may be experienced in stark contrast with past social roles where traditionally women assume total responsibility for maintaining family relationships and all the caregiving for their husbands, children, parents as well as parents-in-law and any other sick or dependent family

members. Women in a cohort raised to identify with the traditional role of housewife might be expected to be relatively more distressed when faced with widowhood or disability (Kessler & McLeod, 1984).

Yet according to Dean, Kolody, Wood and Matt, (1992) it is men who are more affected by the loss of a spouse. They suggest that demographic trends may make widowhood an expected component of women's lifecycle. Because women live longer there is an expectancy of widowhood as well as an availability of role models (other widows) that decreases the distress. By contrast, widowhood elevates mortality rates in men. Women provide more emotional support to spouses as well as practical support (e.g. cooking, cleaning, shopping), which may make men less equipped to cope with the loss. Gutmann (1987) points out that women become more assertive as they age. Older women may therefore have grown to be more independent and better able to handle widowhood than might be expected.

A crucial factor is social support, which is in general associated with health and well-being. Women are more involved with and orientated to friendships than older men (Field, 1999). They differ from men in their ability to form and maintain friendships. Affiliations with others are therefore thought to be central to women's sense of self across the lifespan (Brody *et al.*, 2002). According to Siebert, Mutran and Reitzes (1999) the commitment to a role of friend is significant for predicting life satisfaction, stronger than income or marital status. Although family members make up most of the available social support, friendships may be more important to an older person's well-being. People seek support from others for the role-identity they commit themselves to. Whereas increased reliance on family members may threaten a person's perception as competent, friends seem to be able to offer more positive identity support for their peers. For older women friendships can promote a sense of being valued in the face of failing health and reduced financial resources.

Friendships provide a peer-culture identity that may buffer the effects of stress and encourage preventative health behaviours. Thus despite the fact that many older women live alone, Siebert *et al.* (1999) claim they are often not lonely because of their ability to form and maintain supportive relationships. Again the relevance to this study is a consideration of the impact of dementia on women's ability to maintain valued social relationships.

1.8.3. Dementia Research and Women

The literature review points to a gap in research into the appraisal and coping processes of women with Alzheimer's disease. This may in itself reflect the assertion by Morris (1996) that women have largely been ignored in disability research. From a feminist perspective, Proctor (2001) discusses the 'double jeopardy' of sexism and ageism faced by older women and points out that feminist research has rarely focused on aspects of disability and age. In a qualitative study of how older women with dementia experience the services they receive she used the Voice Relational Method, a listening approach developed by Brown and Gilligan (1993) that explicitly analyses issues of power and adopts a reflexive stance. Including the subjective experience of the women with dementia in research is described as an important aspect of a wider 'person centred' approach that allowed the women to have their views seriously taken into consideration. The qualitative research process therefore plays a role in validating and listening to the person with dementia, which may in itself contribute to well-being.

In another qualitative study Shenk, Davis, Peacock and Moore (2002) examined the life history narratives of two older women, one of whom had dementia. The study draws on narrative accounts of how life-stories are created and reconstructed to communicate aspects of the self to the listener. The themes in both narratives were similar in that they were consistent with gender-based, working class, rural

American cultural values including closeness of family, hard work, ties to the land, and religious faith. The authors described how both women drew on memories to construct stories about themselves that helped them to retain and validate their self-identities. The woman who did not have dementia reconstructed memories of her life in accordance with dominant cultural and personal values, downplaying the ways in which her experiences were 'out of step' with these values.

The woman with dementia presented herself in terms of cultural norms of closeness to family, hard work, strength and resilience. However her cognitive impairment was such that she needed help to co-construct her life story in question-and-answer and affirmation-reaffirmation sequences over several months. The woman with dementia therefore retained a sense of self that was developed in the context of key cultural values, but required greater interaction from the listener to co-construct her narrative. Identity is *"an important coping mechanism in the face of life's disappointments and hardships"* (Shenk *et al.*, 2002, p.404). Ways should therefore be found to support what remains of self-identity in dementia through interaction and validation.

1.9. THE RESEARCH QUESTION

In this study the aim is to capture a subjective account of women's experiences of early-stage Alzheimer's disease and how they manage difficulties with their memory. An examination of how women's past biographies and social roles may affect their appraisals and coping styles is of particular interest. The results will be discussed with reference to models of coping with chronic illness. In doing so it aims to build on a previous study of how men cope with early-stage Alzheimer's disease (Pearce *et al.*, 2002). Differences in coping between men and women may therefore be discussed.

This study will use a qualitative approach to engage women with early-stage Alzheimer's disease in a narrative account of their biography and their experience of memory problems. Qualitative research is particularly suited to give voice to those whose accounts tend to be marginalised or discounted. The method aims to avoid prejudging women's coping processes.

The study will be introduced to the women as research into coping with memory problems. Of interest is how they conceptualise these difficulties. Not all the participants will have been informed of their Alzheimer's disease diagnosis and thus where the women do not frame their difficulties in terms of a dementia it cannot be assumed that they have forgotten or deny the problem. This is where the triangulation of the women's data with interviews of the caregiver will be useful. The caregivers' interviews will give an account of how the difficulties are referred to and what the women have been told of their condition. Other aspects of the carers' interviews are expected to clarify events. Areas where the caregivers' interviews conflict with the women's accounts will be noted.

The review of the literature has shown that people with dementia are active agents in maintaining a sense of self. This study aims to investigate how this applies to women with early-stage Alzheimer's disease. The development of adaptive coping strategies is important in maximising well-being and minimising excess disability. It therefore becomes important to know what factors contribute to the range of responses the women employ. Knowledge of how older women cope with loss of cognitive functioning may therefore inform the provision of social support and counselling for women with early-stage Alzheimer's disease and their carers.

2

METHOD

This study investigates how women with early-stage Alzheimer's disease make sense of their difficulties, and how they manage these difficulties. A qualitative research method has been chosen because this kind of approach concerns itself with meaning, how people make sense of the world and how they experience events. This study is therefore concerned with the quality and texture of experience rather than with identifying cause-effect relationships. The objective is to describe and tentatively interpret the women's experiences, rather than to identify predictors or correlations.

2.1. PARTICIPANTS

2.1.1. Inclusion criteria

The original proposal was to interview ten women with early-stage Alzheimer's disease who met the following criteria:

- Women diagnosed with probable dementia of Alzheimer type as defined by NINCDS-ADRDA (McKhann *et al.*, 1984)
- Living in the community with a partner who did not have dementia and was willing to participate
- Mild cognitive impairment defined by Mini-Mental State Examination score of 18 or above
- Fluency in English
- Able to give informed consent
- Exclusion of other recently diagnosed physical and mental illnesses.

However, an examination of clinical records revealed that the requirement for women to have a partner severely limited the search for potential participants, as many women with Alzheimer's disease known to services were widows. Those women who were still living in the community often lived with a carer (usually a daughter), although in some cases they lived alone. The inclusion criteria were therefore changed to include women:

- Living in the community with a partner or access to a carer who was also willing to participate.

The inclusion of a partner in the research was intended as an additional source of information. It was decided that a carer who knew the woman well could provide equally valid information. This change did not alter the research design, but broadened the scope for additional information. It significantly increased access to potential participants. The woman with Alzheimer's disease was the primary informant in this study. The term 'carer' is used to denote the second informant.

A recent Mini Mental State Examination (MMSE: Folstein *et al.*, 1975) score of eighteen or above determined the criterion of early-stage cognitive impairment. MMSE scores were noted down from clinical records. The MMSE was not re-administered because it was important for the women to be reassured that the study focused on their account of their experience rather than testing their ability.

Participants needed to be fluent in English. This was a subjective criterion, not intended to exclude any ethnic group. It was necessary for the participant to be able to communicate in such a way that allowed for an audio-taped interview to be transcribed and analysed to elicit shared meanings between participants.

The woman's ability to give informed consent was made explicit as an inclusion criterion. Participants with other recently diagnosed illnesses were excluded, as this was thought likely to influence their appraisal and coping processes.

2.1.2. The recruitment procedure

Thirty potential participants were identified, nine of whom took part in this study. The recruitment process commenced as soon as ethical approval was obtained from two Mental Health Trusts in May 2002. The changing of the criteria to include carers, as mentioned above, also required ethical approval, causing some delay in the recruitment. By November 2002 only one participant had been interviewed. Applications were therefore made for ethical approval to recruit participants from two other Mental Health Trusts. This was obtained in January 2003. Due to time constraints it was not possible to meet the original aim of interviewing ten participants. By April 2003 nine participants had been interviewed from three separate Mental Health NHS Trusts, which will be referred to as Trusts A, B and C.

Recruitment in Trust A was shared with two other Trainee Clinical Psychologists aiming to recruit a similar participant group. Presentations about the research projects were given at meetings with each of the three multi-disciplinary teams that provide mental health care for older people in Trust A. A further presentation was given at a meeting of Clinical Psychologists working with older people across the Trust.

Following a meeting with Team 1, three potential participants were referred, but all declined to take part. This team also had a database of clients who were involved in a large study on Alzheimer's disease conducted by a Consultant Psychiatrist. Access to this database yielded another eleven potential participants. Three agreed to take part in this study, three were allocated to take part in the other studies and

five declined to take part. No referrals were received from Teams 2 and 3. However an examination of all the case files for these teams revealed six potential participants, four of whom agreed to take part. Difficulties in arranging a convenient date for one of the carers to attend meant that one of these women could not be included in the study.

In Trust B participants were recruited from a memory clinic. Following a meeting with the Consultant Clinical Psychologist and a Community Psychiatric Nurse, six potential participants were identified, two of whom agreed to take part.

In Trust C a presentation was given to a multi-disciplinary team at a day hospital. Following this meeting, four potential participants were identified by the Consultant Psychiatrist, two of whom agreed to take part. Again, difficulties accessing the carer of one of these women meant that she was not included in the study.

Local clinicians were requested to mention the study to potential participants and seek their permission for me to contact them. In practice this was not always possible, but this did not seem to adversely influence the recruitment process. In only nine instances did the local clinician agree to introduce the study to the potential participant and still six of these declined to take part. Seven of the nine participants that did take part agreed to meet with me without any kind of introduction from their local service.

I established from case files, discussions with referring clinicians or from clinic databases that each potential participant had a diagnosis of probable Alzheimer's disease and met the other inclusion criteria. Information sheets were then addressed to each woman and her partner or carer, and sent to them in the form of a letter. This was followed by a telephone call in the following week to request an

informal meeting at the woman's home. The purpose of these meetings was to explain the study in detail and answer questions the participants might have. If they then agreed to take part, an appointment for conducting the interviews was made. Only one participant declined to take part in the study after such an informal meeting. In three cases the carers specifically requested for the information session and the interviews to be carried out in a single meeting.

2.1.3. Participant profile

Nine women were interviewed in their own homes. Profile demographic data about the participants are given in Table 2. Their ages ranged from 70 to 86 years. All women were white and six were born in the UK. One woman was of Southern European origin and another woman was born in Ireland. Both these women had come to the UK in their early twenties.

Six women were widowed. Of these Brenda and Fiona had their daughters living with them in what was the family home. Caroline lived alone in what had been the family home that had been converted, and her granddaughter lived in the upstairs flat. Deirdre lived with her learning disabled son. She was interviewed in the presence of her daughter, who lived some distance away. Gill was recently widowed and also lived alone; her daughter lived locally. Emma had never married, but lived with her male partner.

Eight women had children and all had worked outside the home at some stage, although Caroline could not remember what her job had been. Anne and Caroline had given up work after they married and had children. The types of job the women had been employed in included printing, sewing, shop-work, publishing, cleaning, clerical and teaching. Emma and Hannah were university educated. The standard school leaving age in the UK for this cohort would have been fourteen. The

somewhat lower ages reported by Brenda and Fiona may be accounted for by their education abroad. It is possible that the somewhat higher school leaving ages reported by Caroline and Deirdre may be accounted for by their memory difficulties.

Table 2 Participant profiles in age, marital status, number of children, previous occupation outside the home, school leaving age and relationship to carer.

Participant	Age	Marital Status	Children	Previous occupation outside the home	School leaving age	Carer
<i>Anne</i>	79	Married	4	Printing	14	Husband
<i>Brenda</i>	81	Widowed 16 years	1	Sewing / Shop-Work	12	Daughter
<i>Caroline</i>	86	Widowed 24 years	3	Not Known	16	Granddaughter
<i>Deirdre</i>	75	Widowed 19 years	3	Shop-Work	16-18	Daughter
<i>Emma</i>	84	Never married	-	Publishing	University	Partner
<i>Fiona</i>	70	Widowed 23 years	3	Cleaning	13-14	Daughter
<i>Gill</i>	74	Widowed 10 months	3	Bank Clerk	14	Daughter
<i>Hannah</i>	74	Married	2	Teacher	University	Husband
<i>Irene</i>	78	Widowed 15 years	1	Sewing / Shop-Work	14	Daughter

2.2. ETHICAL CONSIDERATIONS

Four local ethics research committees approved this study. Documentation of ethical approval is provided in Appendix A.

2.2.1. Informed consent

In this study informed consent was a process of discussion with the referring clinician, carer and woman with Alzheimer's disease. The ability to give informed consent was made explicit in the inclusion criteria. Previous studies have shown that people with early-stage Alzheimer's disease have the capacity to give informed

consent to participate in research when enough care and attention is given to providing them with clear information (Bartlett & Martin, 2002; Goldsmith, 1994; Keady *et al.*, 1995). For this reason an information sheet was sent out to both the woman with Alzheimer's disease and her carer, allowing them time to consider the study before being contacted by telephone.

The information sheet (Appendix B) also made clear that the participant could withdraw from the study at any stage and that the interviews were not part of any treatment. The structure of the information sheets was determined by ethical guidelines and it was recognised that this made them quite lengthy and challenging for a person with mild cognitive impairment. The informal meetings were therefore an important aspect of securing informed consent, providing time to take the participants through the information sheets and giving them opportunities to ask questions. Only after the woman and her carer had discussed the study and indicated that they agreed to take part, were they both asked to sign the consent form (Appendix C).

2.2.2. Confidentiality

The issue of confidentiality was addressed in the information sheet and discussed with the participants. Assurance was given that any information the participant gave would not be revealed to their local clinician without their consent. A guarantee was given that the participant would not be identifiable in any future publications and that audio-tapes would be erased after they were transcribed.

2.2.3. The use of the term 'Alzheimer's disease'

The study was introduced as an investigation of "How do older women cope with memory problems?" In order to get round the problem of participants possibly forgetting, repressing or disagreeing with their diagnosis, efforts were made not to

impose the label of Alzheimer's disease where this might be unwelcome. The woman's own definition of the problem was used, which was established by asking her why she attended the hospital or memory clinic and her view of what was wrong. This was not thought to be unethical as the term Alzheimer's disease would be used if the woman identified her problems as such.

2.2.4. Participants' awareness of their diagnosis

The research question refers to coping with Alzheimer's disease. It was therefore thought desirable that at some stage the women would have been given a diagnosis of probable Alzheimer's disease. This became a difficult issue, as there was often no documentation as to whether participants or their carers had been informed of a diagnosis. Verbal confirmation was given by clinicians that participants had been informed. Nevertheless only Hannah and Irene referred to their difficulties as Alzheimer's disease. Despite prompting Hannah did not mention Alzheimer's disease during the interview, but later referred to it off-tape after the formal interview had ended. Irene was very open about her diagnosis and her daughter attributed this to her attending a support group.

Few carers described the woman's difficulties using the term Alzheimer's disease. Three carers said that although they did not know exactly what was wrong, they wondered whether the woman might have Alzheimer's disease. Fiona's daughter described how she found out her mother's diagnosis by looking at the computer screen in the GP surgery. Despite the fact that the clinicians had given verbal assurances that they had all been informed, Brenda's daughter, Emma and one potential participant (who declined to take part) actively voiced their concern that they were still waiting to be told what was wrong. I did not disclose to participants that the diagnosis was Alzheimer's disease, but offered to bring the matter to the attention of the referring clinician.

Only four of the carers indicated that a clinician had discussed with them the woman's diagnosis of Alzheimer's disease. This research study therefore cannot address how women cope with a diagnosis of Alzheimer's disease. It examines how women make sense of and manage the difficulties referred to as memory problems.

2.2.5. Feedback and risk management

When distress or unmet needs were identified, I offered to contact the local clinician. Issues that were referred back to local clinicians were a husband reporting difficulties coping, a request for a day centre place, domestic tensions that a daughter recognised as detrimental to the well-being of her mother and instances where it appeared that the clinic had not provided feedback about the woman's diagnosis. Permission to discuss these matters with the local service was sought from the participants. Distress and unmet needs were identified throughout the recruitment process. Not all those potential participants who had issues that needed to be referred back to their local clinician actually took part in the study.

The possibility of the interviews bringing up potentially distressing material was discussed at the informal meetings and was included in the information sheet. The structure of the interviews was flexible and aimed to also include discussion of pleasant material. After the interviews the participants and carers were given an opportunity to ask any further questions and talk about the interview experience. A contact telephone number was included in the information sheets in the event of further questions arising after the interview. A summary of the research findings was made available to all the participants, together with a message thanking them for their contribution to the study (Appendix D).

2.3. INTERVIEWS

2.3.1. The interview schedule

The design of the semi-structured interview schedule was influenced by guidelines provided by Smith (1995) and the methodology of Interpretative Phenomenological Analysis (IPA: Smith *et al.*, 1999), which relies on open-ended and non-directive questioning. The purpose of such questions was to provide the women with an opportunity to share their personal experience. The schedule therefore did not dictate the actual interview process, but provided a broad framework of questions that guided the participants to the areas relevant to the research question. In practice the order and wording of the questions was flexible, allowing maximum opportunity for the participants to tell their story. The aim was to enter the psychological and social world of the women with dementia.

The research question indicated that the interview should cover four broad areas: background information, the appraisal of memory problems, the effects of memory problems and coping with these difficulties. It was then decided what information needed to be covered for each of the four areas. This provided a basis for appropriate questions, which aimed to be neutral rather than value-laden or leading. An effort was made to think about wording questions in such a way as to avoid jargon and to use open questions wherever possible. Broad questions were followed by prompts if the woman had difficulty understanding.

In order to establish rapport it was decided to start the interview with questions focussing on the woman's background. The questions probed for broad biographical information and specifically elicited accounts about children, past employment, education, interests and valued achievements. To get an understanding of how the woman made sense of her difficulties, questions in the next section included items about how she came to be seen at the clinic, what the clinic had told her about her

difficulties, what she thought about this, how she thought her family saw the situation and questions about medication. Questions about how her memory problems affected her focussed on day-to-day activities and tried to probe for possible impacts on her relationships and social roles. The last section about coping included questions about what she did when difficulties occurred, what made things worse and what helped. Where appropriate, questions that were likely to elicit negative feelings were followed by questions about positive topics, experiences or achievements.

The interview with the carer focused on the woman with Alzheimer's disease and the questions in the carer's interview schedule therefore mirrored those of the woman's interview. Some effort was made to acknowledge the stress the carer was under. The interview schedules were reviewed by a supervisor and were made available to the local research ethics committees. Copies of both interview schedules are located in Appendix. E.

2.3.2. The interview procedure

All the interviews took place in the home of the women with Alzheimer's disease. The women and their carers were interviewed separately in all but one case. Deirdre's daughter asked to remain in the room during her mother's interview, as it was the only room in the house that was considered habitable. In all cases the woman with Alzheimer's disease was interviewed first. In order to orientate her, a brief introduction as to the structure of the interview was given. This same information would also have been given at the earlier informal meeting. The four sections of the interview were displayed in bold large print (pt 20) as follows:

1. Talking about you and your past
2. Talking about what you think about your memory problems
3. Talking about the daily difficulties of memory problems
4. Talking about how you manage these difficulties.

Each section was introduced very broadly using the words on the sheet (e.g. *“Let’s start by talking a bit about you and your past”*). This would often be sufficient to get the participant talking. I then guided the conversation with specific questions from the interview schedule. The length of the interviews varied from 23 to 62 minutes, depending on the preferences and talkativeness of the women.

I started the interview with the carer by summarising the biographical information the woman with Alzheimer’s disease had talked about. This was a useful approach as it would prompt the carer to clarify or contradict the information. It was particularly useful in orientating the woman’s account in time and place. The length of these interviews varied from 29 to 49 minutes.

2.4. MEASURES

Profile data of the women’s scores on screening measures for cognitive functioning, carer rated ability in activities of daily living and self-reported mood are presented in Table 3. These same measures were used in a previous qualitative study of appraisal and coping processes in men (Pearce *et al.*, 2002). It was decided to use these measures to assist in situating the sample, and consider similarities or differences between the two studies in areas other than gender. A description of these measures is given below.

2.4.1. The Mini-Mental State Examination

The MMSE is brief screening measure for assessing cognitive impairment. It assesses orientation, memory and attention, and includes items that require the person to name objects, follow written and verbal instructions, and copy complex shapes. It's brevity and high inter-rater reliability ($r=0.88$, Folstein *et al.*, 1975) makes it a popular clinical and research tool.

Hodges (1994) advocates the use of MMSE scores as an approximate index of impairment, where scores between 18 and 24 are classified as mild impairment and scores above 24 as minimal impairment. Recent MMSE scores of the women in this study were obtained from clinical records. Table 3 shows wide variability in the women's MMSE scores, ranging from 20 to 29. Deirdre and Emma scored in the minimal impairment range, whilst the rest of the scores indicate mild cognitive impairment.

Table 3 Participant scores on the Mini-Mental State Examination, the Bristol Activities of Daily Living Scale and the Hospital Anxiety and Depression Scale.

Participant	MMSE /30	BADLS /60	HADS Anxiety	HADS Depression
Anne	22	13	1	0
Brenda	20	18	16	9
Caroline	21	25	3	13
Deirdre	25	23.5	7	4
Emma	29	25.5	12	4.5
Fiona	23	10	1	4
Gill	22	12	5.5	5
Hannah	23	19	0	0
Irene	23	23	0	2

2.4.2. The Bristol Activities of Daily Living Scale

The Bristol Activities of Daily Living Scale (BADLS: Bucks, Ashworth, Wilcock & Siegfried, 1996) is a carer-rated instrument designed for use in the community. It assesses the ability of a person with dementia to undertake twenty common daily living tasks. Essentially it is a measure of the non-cognitive aspects of dementia, tapping into four basic components: instrumental activities of daily living, self-care, orientation and mobility. It gives an indication of the extent to which the person with dementia is dependent on her carer. A particular problem with an informant-based scale such as the BADLS is that it relies on the informant's own memory and s/he may be motivated to present the person in the best possible light, or worst.

An evaluation of the scale by its authors (Bucks *et al.*, 1996) found that carers reported the BADLS to have good face validity. Concurrent validity was assessed by correlating the BADLS with ratings of observed task performance ($r=0.65$, $p=0.004$) and the MMSE ($r=-0.67$, $p<0.001$). Test-retest Kappa scores for the items ranged from 0.27 to 0.94. The majority of the items had a good (0.61-0.8) or very good (0.81+) Kappa scores. The BADLS was therefore found to have good test-retest reliability. Scores showed no significant relationships with gender or years of education, but there was a significant relationship between the BADLS scores and the age of the person with dementia.

The carer is asked to consider the ability of the person with dementia over the previous two weeks and rates this according to four categories: able (no assistance needed), able with instructions/prompts, unable even with instructions, and not applicable. It therefore recognises that the items may not be appropriate to everyone. Where a carer deems that an item is not applicable, a score of independence for that task is given, as the authors point out that it would be

inappropriate to make assumptions about the person's level of dependence on such items.

In this study the carer was given the BADLS to complete whilst the woman was being interviewed. Verbal and written instructions were provided for the completion of the scale. The carers were assured that help would be given with if they had difficulties with the questionnaire. Although the authors of the scale describe it as easy to use and relatively short, it should be remembered that carers are often themselves elderly. I therefore wanted them to have sufficient time to consider the scale. Prior to starting the carer's interview the BADLS was reviewed. Some reported difficulty in categorising the ability of the woman on some tasks, but an acceptable solution for this was to locate ability for these items in between two categories. This accounts for some of the half point scores in Table 3. Some carers commented that they found the BADLS helpful in thinking about the woman's ability, but others admitted to feeling distressed at being confronted with examples of possible disability in the future that they had not yet considered.

Total possible scores range from 0 (total independence) to 60 (total dependence). Table 3 shows that the women had a wide range of functional ability in daily living skills. Scores ranged from 10 (the most independent score, obtained by Fiona) to 25.5 (the most dependent score, obtained by Emma).

2.4.3. The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS: Snaith & Zigmond, 1994; Zigmond & Snaith, 1983) is a brief 14-item measure for both anxiety and depression in a single scale. It was developed for patients with physical illness and purposefully excludes questions relating of the physiology of anxiety and depression, as these may confound physical disorders with mood state. The anxiety scale therefore

focuses on restlessness and anxious thoughts, whilst the depression scale focuses on loss of interest and diminished pleasure.

The respondent is asked to consider her emotional state over the past week and rates each item on a four-point scale, which is scores from 0 to 3. This yields separate scores for anxiety and depression ranging from 0 to 21.

An evaluation of the scales by Zigmond and Snaith (1983) suggests good reliability and validity. Physically ill patients who were assessed as not having a mood disorder had similar scores to a sample of non-patients without a mood disorder. HADS scores were compared with psychiatric diagnoses, which indicated that severity ratings correlated with psychiatric judgements (0.70 for depression and 0.74 for anxiety). Internal consistency correlations in the anxiety subscale ranged from 0.41 to 0.76, and 0.30 to 0.60 for the depression subscale.

Several studies have assessed the validity of the use of the HADS with older people. In administering the scale across a range of different groups of participants, Spinhoven *et al.* (1997) found no evidence of a clinically-relevant effects of age on HADS scores. Kenn *et al.* (1987) reported the HADS depression scale to be a valid instrument for assessing an elderly psychiatric population. Previous studies have also used the HADS to assess levels of anxiety and depression in people with dementia (Clare *et al.*, 2002; Wands *et al.*, 1990).

Nevertheless in this study I observed some difficulties in using the HADS with people with dementia. The HADS was presented to each of the women after their interview. Although the written instructions ask for quick, 'immediate' responses, this is an inappropriate demand on elderly people with cognitive impairment. It was difficult for them to hold in mind that their responses should reflect their emotional state over the past week. Only Fiona was able to complete the scale herself with

minimal assistance. Hannah, who had been a language teacher, was quite able to read the items and even commented on the grammar, but needed help to orientate her to using the response scales. In all other cases I assisted by reading each item out and pointing to the scale of response options. Some items presented the women with too much information to hold in mind and needed repetition. Invariably the women wanted to discuss items, and in order to retain good rapport this was not discouraged. Women would often verbalise a response that did not precisely fit the categories of the scale. I would then reflect back to the woman an 'either/or' option from the scale. For example, the woman might respond to "*I feel tense or wound up*": "Well I suppose sometimes I do, but other times I don't". The two options would then be presented as: "Do you feel tense or wound up a lot of the time or only occasionally?" This would often facilitate the categorisation of her responses, but if this did not work the woman's response was validated and I allocated a score that lay in between the categories. This accounts for the half point scores in Table 3. Despite this gentle approach some women commented that they found the task difficult and were apologetic about "Not having been very helpful". I tried to reassure them, acknowledging the difficulty of the task, giving positive feedback that they had done well.

According to Snaith and Zigmond (1994), sub-scale scores below 8 points may be considered as non-cases, 8-10 as mild cases, 11-14 as moderate cases and scores of 15+ as severe cases. Table 3 shows wide variation in the women's HADS scores. Anxiety scores ranged from 0 to 16, with two of the women (Brenda and Emma) meeting case definition. Depression scores ranged from 0 to 13, again with two women (Brenda and Caroline) meeting case definition.

Brenda's HADS scores indicate severe anxiety and mild depression. A particular theme of her interview was one of "worry" about domestic tensions. Emma's HADS score indicates moderate anxiety and a theme in her account was the potential for

conflict with her partner and worry about how long they could continue to live “in harmony”. Caroline’s HADS scores indicates moderate depression. A major theme of her interview was one of loneliness.

2.5. DATA ANALYSIS

2.5.1. Interpretative Phenomenological Analysis

The interviews were transcribed and analysed using Interpretative Phenomenological Analysis (Smith *et al.*, 1999). IPA was chosen as opposed to another qualitative method for several reasons. From a practical point of view, the separation of the data collection and analysis phases in IPA is advantageous. Given the scope and time constraints imposed on this research, the theoretical sampling approach of Grounded Theory (Strauss & Corbin, 1990) was not possible. Furthermore, this study proposes to make comparisons with previous research that also used IPA (Clare, 2002a; Pearce *et al.*, 2002).

Interpretative Phenomenological Analysis (IPA) is informed by the philosophy of phenomenology. It is based on the notion that perception is guided by multiple assumptions about the self, others and the world.

“Phenomenology is interested in elucidating both that which appears and the manner in which it appears. It studies the subject’s perspectives of their world; attempts to describe in detail the content and structure of the subject’s consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings.” (Kvale, 1996, p.53).

Phenomenological research attempts to get inside the participant’s experience on the basis of her description of it. The participant’s account becomes the phenomenon under investigation (Willig, 2001).

With IPA the phenomenological analysis also involves interpreting the participant’s experience. The approach acknowledges that the researcher is involved in both

shaping the interview and interpreting the responses. The aim is to access the meanings in the participant's account, meanings which are not transparent, but emerge via an interpretative process which involves the investigator in a sustained engagement with the data (Smith *et al.*, 1999). Access to these meanings is therefore both dependent on and complicated by the researcher's own conceptions. Acknowledging and reflecting on how the researcher brings his own ideas, beliefs and values to the analytic process can be viewed as a particular strength of the approach.

Analytic engagement with the data is a process consisting of a series of steps whereby themes are identified and integrated into meaningful clusters, first within and then across cases (Willig, 2001). Individual transcripts were read and particular aspects of the woman's appraisal of, and coping with memory problems were noted down, staying as much as possible with her own words. These notes were prepared into a summary list that formed the basis of the subsequent thematic analysis. The list was examined with a view to grouping the notes into themes. This process often provided several possible solutions and required some careful thought as to which was the best 'fit' for the data. Closely related themes were grouped together as sub-themes in a hierarchy. Wherever possible the woman's own words were used to label the themes. The transcript was then reread and instances where the identified themes occurred were noted down. This provided a further check on how the themes could fit together with the data and allowed for changes to improve the fit.

Other issues that came up in reading a transcript were noted down separately. These included any confirmation, clarification and contradiction with the carer's account, biographical information that might be of relevance to coping style and reflections about the direction of the interview. These notes were examined

separately, allowing for further reflections about the woman's account and my role as the researcher in the process.

Once this process was completed for each individual transcript, analysis across the interviews involved the preparation of a list of all the themes taken from each of the individual summary lists. These were rearranged into a coherent set of themes extending across the interviews, grouped into superordinate themes and sub-themes. Some of the themes unique to individual transcripts were omitted from the group analysis. This again required careful thought about the best 'fit' solution to the analysis. The individual transcripts were then reread and instances of the overall list of themes were noted down, with further changes being made where necessary. A list of extracts of all instances of each theme for the women's interviews was prepared. Individual extracts were then chosen to illustrate each theme.

The carers' interviews were examined separately after each thematic analysis of the individual women's transcripts was completed. This allowed me to note down ways in which the carers' accounts clarified, confirmed or contradicted the women's narratives. Examples of this were used to illustrate the results. These notes also raised several points that are addressed later in the discussion in Chapter 4.

2.5.2. Validity

A comparison of the woman's and carer's transcripts provided a means for triangulation. A consideration of how the carer's data elaborated, supported or contradicted the woman's data increased the validity of the study.

Another aspect of validity was to check on the extent to which the data collection and analysis really addressed the research question. In this study two supervisors read the transcripts to provide credibility checks and audited whether the process of

analysis was systematic. Both supervisors have a clinical and academic background in the psychology of ageing and have published qualitative research using IPA on the subject of coping with dementia.

Qualitative research assumes that it is impossible for a researcher to position himself outside of the subject matter. A researcher will inevitably have a relationship with or be implicated in the phenomena he studies. Therefore I, as the researcher, needed to reflect upon my own standpoint and identify ways in which this shaped the research process and findings. Reflexivity ensures that the research process is scrutinised and my role in the process is continually reviewed.

2.5.3. The researcher's perspective

As the researcher in this study, my theoretical perspective is based on my review of the literature. The influence of stress-coping models is implicit in the title "Appraisal and coping processes in women with early-stage Alzheimer's disease". I also acknowledge the influence of previous qualitative research in coping with dementia. I am particularly familiar with the studies by Clare (2002a) and Pearce *et al.* (2002). These studies described strategies whereby people with early-stage Alzheimer's disease attempted to maintain their sense of self and integrate changes into a new self-concept. I also draw on a theoretical perspective that pre-morbid coping styles may influence the way a person manages the difficulties of dementia.

My personal perspective is that of a white European gay man. My background in community social work, sexual health advice and counselling in HIV brings to this study an interest in how minority or disadvantaged social groups find a voice and assert their rights. During the course of this research I have come to question the extent to which older people with dementia are given choice, respect and dignity within the health service. By drawing parallels with the HIV field, older people with

dementia do not appear to enjoy equal rights in terms of having a voice in their care and choice in whether or not to be diagnosed, and with whom that information may be shared. The way a person experiences a lack of choice, respect and dignity will be relevant to appraisal and coping in early-stage Alzheimer's disease. By considering coping choices in the context of a disease that is socially appraised as stigmatising, I would expect to find that people in the early-stages of Alzheimer's disease will be aware of their difficulties, but will be reluctant to name it as a disorder and will be motivated to minimise their symptoms as normal ageing.

In naming my theoretical and personal perspectives on the research question, the challenge in qualitative analysis is to set aside or "bracket" these pre-conceived biases and assumptions (Husserl, 1931). The IPA approach tries to do this, but also acknowledges that there will inevitably be an element of interpretation, which requires me as the researcher to reflect on my position. The credibility checks by the two supervisors have been useful in pointing out instances where pre-conceived assumptions were imposed on the data and any tendency to stray from a phenomenological perspective.

3

RESULTS

In this chapter the themes relating to the women's appraisal of their memory problems and coping processes are presented. Eleven themes emerged from the narratives and these are described using quotes from the women themselves to reflect their experience. The structure of the interviews also allowed the women to present their life-stories. Where relevant, consistencies between present-day coping and the biographical themes are noted. The emphasis is on the women's subjective account of their difficulties. The interviews with the carers provided additional information that clarified, confirmed or contradicted the women's accounts. Some of the descriptions of the themes therefore also contain quotes from carers.

Quotations are used to illustrate the themes and these are attributed to each woman by name, as indicated in brackets. It should be noted that these are not their real names. A profile of the women and the names given them by the researcher is presented in Chapter 2. It is hoped that this will help bring the analysis alive for the reader. The annotation '...' indicates where text was edited for the sake of brevity or to omit the investigator's prompts. Where relevant some interaction between the women, carers and investigator is presented. Square brackets '[]' are used for clarification and to place the quotes in context.

The themes are not discrete categories, and many of the quotes can be categorised as aspects of several themes. Table 4 indicates which of the themes and sub-themes were observed in each woman's account, grouped into three higher-order themes. The label of a theme was often juxtaposed against its antonym, in which case it is presented as a continuum (e.g. connectedness to disconnectedness). The analysis involved a degree of interpretation on the part of the investigator. These

interpretations are made tentatively and should not be viewed as facts. This is acknowledged in particular with regard to the grouping of the data into three higher-order themes.

Table 4 The incidence of the eleven themes and sub-themes in each of the nine accounts, grouped into three higher-order themes. The women are identified by the first letter of their name.

Themes	Participants								
	A	B	C	D	E	F	G	H	I
CONNECTEDNESS									
1. DISCONNECTION WITH THE PAST		X	X	X	X	X	X	X	X
Awareness of not remembering		X	X	X	X	X	X	X	X
Uncertainty - confusion		X	X	X			X		X
2. SUPPORTIVE FAMILY RELATIONSHIPS	X	X	X	X	X	X	X	X	X
Reliance on family	X		X	X				X	X
Doing things together	X			X			X		
Proxy memory				X	X		X	X	
Telephone as a lifeline				X					X
Loss of family contact		X	X		X		X	X	
People cannot always be relied on			X				X	X	
Potential for conflict	X	X		X	X			X	X
3. FRIENDS AND NEIGHBOURS	X	X	X	X		X	X	X	X
4. SOCIAL ROLES		X	X			X		X	X
5. FAMILIARITY					X	X	X	X	X
Routine					X	X		X	X
Staying local					X	X	X		X
PROTECTIVE STRATEGIES									
6. IT'S NOT SO BAD	X	X	X	X	X	X	X		X
Remembering the things that are important	X	X		X	X	X	X		X
It comes back	X	X	X	X					
7. ISN'T IT FUNNY!		X	X	X			X		X
8. IT'S NOT REALLY AN ISSUE	X	X	X			X	X	X	X
Not thinking about it – one day at a time	X		X			X	X	X	X
Not talking about it	X	X	X			X		X	X
ACCEPTANCE									
9. JUST PUT UP WITH IT			X	X			X	X	
10. NORMALISING		X	X	X	X	X			X
That was a long time ago		X	X	X		X			X
Others have difficulties too				X	X				X
11. PROBLEM SOLVING	X	X	X	X	X	X	X	X	X
Staying occupied	X	X	X	X	X	X			X
Writing a few things down				X	X	X	X	X	X
Keeping things to hand				X			X		
Checking		X				X			
Using medication	X	X	X	X		X		X	X

The higher-order theme of Connectedness relates to the women's attempts to maintain a sense of self derived from attachment to family and friends, affiliation with social roles, familiarity with surroundings and a sense of continuity with the past. The themes grouped under this heading illustrate how the women experienced their difficulties in terms of connectedness, and applied coping strategies that relied on maintaining a connection with others and their environment. Themes relating to reports that memory loss was not a problem are grouped under the higher-order theme Protective Strategies and may be interpreted as attempts at minimisation and avoidance. Themes that related to the women's self-statements about acceptance, normalisation of their difficulties and use of problem-solving strategies are grouped under the higher-order theme Acceptance.

It should be noted that the investigator used the term 'memory problems' during the interviews with the women and their carers, unless they themselves referred to Alzheimer's disease. Only one woman talked about Alzheimer's disease in her interview. Idiosyncratic explanations for memory difficulties were lost in the group-wise analysis. Therefore, in order to provide a context for the main body of the results, an overview of how the women accounted for their difficulties needs first to be given. This will be followed by a description of the themes and sub-themes grouped in each of the three higher-order themes. The relationship between the three higher-order themes is interpreted in a model presented at the end of this chapter.

3.1. THE WOMEN'S ACCOUNTS OF THEIR MEMORY PROBLEMS

All the women acknowledged to a greater or lesser extent that they had difficulties with their memory, although some women thought their memory loss did not necessarily cause them problems in day-to-day living. When asked what they thought was happening to them, various explanations for memory problems were

given including ageing, bereavement, loneliness, worry, a previous head-injury and Alzheimer's disease. However, most of the women also admitted that they did not really know what was happening to them. Nested in these accounts are themes that relate to minimisation, normalisation, acceptance, concerns about connectedness, and avoidance.

3.1.1. Ageing

Two of the women accounted for their difficulties in terms of normal ageing, either because others had explained their difficulties to them in this way or because memory loss was expected in old age:

'He [GP] just said it could be old age. He said that he really can't put a place on what is really causing it.' (Deirdre)

'Well I just thought that people did [lose their memory in old age].' (Emma)

However, there was also a recognition that memory loss was just one of a number of challenges the women faced in ageing, including inactivity, immobility, other ailments and vulnerability in cold weather. Becoming inactive and no longer engaging in previously valued activities was described as a normal part of ageing:

'I'm afraid, well see I'm in my seventies now and I'm getting lazy.' (Hannah)

The possible negative effect of inactivity and understimulation was recognised by some of the carers as a major concern:

'I can see that life I suppose must be quite mundane and boring for her and it didn't used to be. And I think, although she hasn't said so, that is probably how she feels...I just think that she's not getting enough stimulation because of that...I suppose it's probably not going to improve her condition. Not that, I'm not saying, I'm not sure if anything could improve her condition, but stop it deteriorating more rapidly shall we say. I think everyone needs some sort of stimulation of some sort.' (Fiona's daughter)

Immobility was described as a major obstacle to staying connected with the outside world:

'O goodness, I'm not able; I haven't lost my memory about that. I find it difficult to do anything you know. And I do have this disease, which is a bit hampering, which they call osteoporosis, which does make it difficult to move about. I can't walk; I couldn't hope to walk very far. I can hardly walk across the room without using a stick now...I was driving a van and I went all over the place. And I've not got that movement any more.' (Emma)

The impact of immobility on social isolation was also noted by the carers:

'I know she feels trapped in the house. That's her big problem. She doesn't feel that she can get out like she used to.' (Gill's daughter)

Most of the interviews took place during a particular cold spell over the winter and the women commented on the impact of this on their ability to get out of the house:

'Now in the winter it's cold, I don't walk very much, that's why [she does not go out].' (Brenda)

For Fiona this sense of vulnerability was based on a previous experience of slipping and falling on the ice. Her daughter worried that isolation during the winter months would cause her mother to lose skills that she might not regain:

'God you know, do these winters months have a big impact now forever more?...Or will that be something that's going to have a long term effect on her because she won't have remembered going out and getting on a bus by herself for such a while.' (Fiona's daughter)

3.1.2. Bereavement

Six of the women were widowed. Few of the widows expressed much distress over the loss of their husbands, most of whom had died many years ago. In fact it was noticeable how late husbands were almost absent from some life-stories. However,

Gill related her memory difficulties directly to the distress of losing her husband ten months ago:

'I think the trouble with me is, it relates to when my husband died...I do keep reverting back to that in my mind...I actually see him die. I think that was the worst part.' (Gill)

Her daughter explained that her mother had memory problems prior to the death of her husband, but the distress of this had compounded her mother's difficulties.

Emma expressed fear about losing her partner as a threat to her connectedness, as well as concern for him should she die first:

'I do worry a lot as to which one of us will die first and leave the other, hoping that they won't be in any dire difficulty or distress or misery.' (Emma)

Of interest here is that her partner thought that Emma's cognitive decline was related to the death of her sister three years ago, a distressing event that was notably absent from Emma's account:

'Well I think frankly it has something to do with her present state of mind. It's too much of a coincidence. It happened all more or less at the same time...The memory loss and the death of her sister were very close together. And it's so sudden too. I mean I was very much taken aback by it.' (Emma's partner)

3.1.3. Loneliness

Caroline accounted for her memory difficulties in terms of loneliness. The recurring theme of loneliness was particularly noticeable throughout her life-story:

'Oh yes I enjoyed it [school] and then I was left on me own... but it was loneliness. I was lonely, didn't know what I was doing...When I got married it was alright...I was young when I met him and then he died.' (Caroline)

Disorientation in time appeared to interfere with her ability to remember that she had been married for over forty years. She was lonely now because she missed her family. Although her granddaughter lived in the flat upstairs, her experience was that she was left alone much of the time:

'I don't know [why she has memory problems]. I suppose it was because I was the only child and you know, when they [the children] got married I didn't see much of them...I don't know. Well I suppose I see nobody and I forget.'

(Caroline)

3.1.4. Stress

Brenda accounted for her memory problems in terms of worry. English was not her first language and the words 'worry' and 'upset' were used interchangeably to describe her distress. Her worries were about her connectedness. Her daughter, son-in-law and grandson lived with her in her flat and she worried about her daughter's marriage. I witnessed at first hand a domestic argument and Brenda's distress about this. She described being verbally abused by her son-in-law and prevented from taking on a more active caring role as a grandmother:

'Really, it's so much worry, that's why it make me sometimes forget...You know, when he started to shout at me, darling, yes. I get worried, upset, that's why.' (Brenda)

Neither Brenda nor her daughter had yet been informed of the Alzheimer's disease diagnosis. In the absence of professional help, Brenda had constructed her own explanation of forgetfulness in terms of stress. According to Brenda the doctors had given her this explanation:

[The doctor said] *"Try to be relaxed and you'll be alright."*

[The psychiatrist said] *"You'll be alright, because you worry too much."*

(Brenda)

3.1.5. Previous head-injury

Fiona appeared to be unaware of her diagnosis and her daughter confirmed that she had never been party to any discussion about Alzheimer's disease when she attended her mother's hospital appointments. In the absence of a diagnosis, Fiona looked for an explanation for her memory problems in terms of a fall on the ice:

'No I haven't got any illness...The one thing that did do it to my memory is that when I was quite young I fell; hit the back of my head...That could have had an effect on it. It probably had.' (Fiona)

3.1.6. Alzheimer's disease

Irene was the only participant who described her difficulties as Alzheimer's disease during the interview:

'Well it's Alzheimer's, that's the only name I know...It's a thing that you're forgetful, that's the only way, you know. I thought, you know, a bit forgetful and you make out like.' (Irene)

Noticeable in her account was that acceptance appeared to be a function of her connectedness to her family, friends and environment. She explains how she did not experience Alzheimer's disease as a problem because of the help she received from her daughter and friends, and felt safe in her local area where she had lived most of her life. Her daughter attributed her mother's openness about her diagnosis to attending a support group piloted by the day hospital. However she also acknowledged that Irene engaged in some protective strategies such as minimisation because of her frustration and embarrassment.

3.1.7. Not knowing

The women's sense of not knowing what might be causing their difficulties may be attributed to a combination of lack of information and forgetfulness. Gill's account

points to the interaction between forgetfulness and ambiguous communication in her not knowing about her diagnosis:

'I can't remember now. I know they [staff at memory clinic] have chatted to me, but to say I could say what it was now [memory problem], I don't think I could...I think there is a name for it. I think I've read about it in fact.' (Gill)

Her daughter reported that she had been present at all her mother's memory clinic appointments and her difficulties had never been explicitly named as Alzheimer's disease. She hoped that her mother had not read a recent newspaper article about Alzheimer's disease as she felt this might upset her.

Neither Emma nor her partner had been informed of her Alzheimer's disease diagnosis. In the absence of information she tried to make sense of her difficulties by excluding falls and illnesses, concluding later that it could just be old age:

'I don't really remember how or why I lost my memory. There was never a fall or any sudden disease.' (Emma).

However, the most common explanation for not knowing what might be causing their difficulties was given in terms of it not being talked about. This is a theme that is discussed below as an example of a protective strategy.

3.2. CONNECTEDNESS – THAT'S WHY I DON'T WORRY

The higher-order theme of Connectedness relates to identity and draws together a collection of five themes that emerged from the women's narratives: disconnection from the past, supportive family relationships, friends and neighbours, social roles and familiarity. The importance of family was also present as a biographical theme. Memory problems were experienced as a threat to the women's connectedness to their past and their families. The women attempted to cope with this threat by maintaining their attachment to family and friends, continuity with social roles and

familiarity with their surroundings. These themes placed the women on a continuum from connectedness to disconnectedness. Threats to connectedness were experienced as distressing. By contrast, higher levels of connectedness meant that the women did not necessarily experience memory loss as a problem.

3.2.1. Disconnection from the past

In the early stages of Alzheimer's disease the women experienced impaired episodic memory as a threat to their connectedness with people and events from the past. This theme is described by way of two sub-themes: the women's awareness of not remembering and their uncertainty or confusion about details.

Awareness of not remembering

Some of the women were acutely aware of their memory loss and at times showed some distress about this:

'I don't know exactly when, but fairly recently, I knew I had lost my memory [stresses the word lost] and it meant that a large, a big portion of my life I simply couldn't recall.' (Emma)

Aspects of the interview process that focused on the women's biographical details were experienced as somewhat challenging, and some of the women commented on this:

'You know you've caught me a bit late in the day for all this...You're asking me to remember what I've forgotten [laughs].' (Hannah)

I interpreted this as a gentle request to ease up on my questioning style. Laughter in such situations may be an attempt to mask embarrassment, which is discussed below as a protective strategy.

Uncertainty – confusion

During the interviews there was ample evidence of uncertainty and confusion. This was often expressed as an internal dialogue whereby the women questioned themselves aloud about events, revealing a process in which they gave themselves time to apply some effort at retrieval:

'Did I go? I forget. Did I go? I did go [to see the doctor].' (Brenda)

'I've got to think about that [whether husband was retired before she had retired]. I think he'd retired [pause] 'cause he was five years older than me, so obviously.' (Gill)

Caroline's memory impairment appeared to be more severe and she continually needed to question herself and at times became quite distressed by this. She mentioned her son's name and was immediately beset by doubt whether this was in fact his name or her late husband's name:

'Was it my son or my husband? [Sounding a bit surprised/distressed] I don't know!' (Caroline)

Her family was important to her, but she was uncertain about exactly how many children she had:

'I don't know if I had any more [children]. I remember three, but I think it was three...Have I got two daughters?...I got I think, is it two daughters and a son?...I've got two daughters, I know. Two daughters and a son I think.' (Caroline)

3.2.2. Supportive family relationships

This theme illustrates how supportive family relationships were central to the women's ability to maintain a sense of self. It is succinctly summarised by Anne's comment on the importance of having her family around her:

'So I suppose that's why I don't worry.' (Anne)

The social support available to some of the women appeared to cushion the effects of memory problems to the extent that some women, although they were aware of their memory problems, did not necessarily experience this as a problem:

'Well admittedly Janice [daughter] don't leave a lot for me to do, but you know, I suppose it's bit easier, but I really don't worry about a lot very often.'
(Irene)

The family was thus an essential source of practical and emotional support, the presence or absence of which was seen as directly contributing to their sense of well-being:

'They're very, very good to me. In the way of helping me, you know, so that's it. I can't fault nothing there...He's very good and she's very good and I'm quite happy you know with things as they are.' (Irene)

'When you're left on your own, it's misery, it is. I'm left on me own and I don't like it. I don't know what I'm doing half the time...I don't see much of 'em [family] and it's depressing.' (Caroline)

A supportive family also provided a sense of continuity connecting the generations. This is perhaps best illustrated by Emma, who in the absence of a family of her own adopted her partner's family to fulfil this role:

'I'm always looking forward to good things happening to his family...I've never thought of having a family of my own very much. Never wanted to very much. But I've always been interested in him [partner] watching, going to see his children doing things.' (Emma)

What is interesting about Emma's biographical account is that closeness to family stands out as an important theme as she reminisces about her grandmother, mother, aunts and uncles. However, she never wanted to get married, and pointed out:

'I was never a lesbian, but I did used to have one or two quite close female friends, well among my [university] pals and then one or two friends in London.' (Emma)

Her partner explained that she was one of the first women to graduate from a prestigious university and came from a family of dominant women. She lived with her sister until the sister's death three years ago, an event that he felt coincided with her cognitive decline. Despite this, the sister did not feature in Emma's account.

The theme has several sub-themes that lie on a continuum of connectedness verses disconnectedness: reliance on family, doing things together, proxy memory, telephone as a lifeline, loss of family contact, the unreliability of others and the potential for conflict.

Reliance on family

In this sub-theme the women describe their reliance on their family as a major coping strategy. This was particularly evident in the carers' control over matters medical. When faced with tasks that they no longer felt able to manage independently the women abdicated responsibility to their children or partners:

'I admit I don't have a lot to do 'cause Janice is very good you know, she helps me.' (Irene)

Her daughter added that her mother would become distressed if she asked her to take back any responsibility for the tasks she had taken over:

'She doesn't want any responsibilities...In fact if you give her anything to do that she would consider to be responsibility that would freak her out, she's not interested. I deal with all the money things, the bills. I can't send her to get any shopping, if I had to ask her to get some shopping she'd be, "Oh, oh what am I going do?"' (Irene's daughter)

Hannah described how her husband had taken over many of the daily responsibilities, such as shopping and cooking. When asked if there was anything she looked forward to that day she laughed and replied:

'I don't know what today's programme is actually.' (Hannah).

Over-reliance on others could therefore have a detrimental effect by disengaging the women from any active involvement in decision-making. Hannah provided an example of how reliance on her husband in medical matters disengaged her from her treatment. She explained that she did not know what the doctor said about her memory problems because:

'My husband goes and collects the tablets, so I don't know.' (Hannah)

Doing things together

Doing things together with family was a coping strategy that allowed the women to accept and expect help as the natural order of things, as opposed to feeling that they had become a burden. If carers took over all tasks this could be considered as interference, whereas doing things together was appreciated. This kind of help could be experienced as unrelated to any disability:

'She don't interfere. Don't get me wrong there. My daughter and I both go out shopping together. She's got a car. Saves me walking.' (Anne)

I noted that, when asked, the women invariably said they did not receive any 'help'. The notion of 'help' seemed to be interpreted by the women as assistance from outside agencies, rather than that which they received from their families.

Proxy memory

The women relied on their families as a proxy memory to remind them of things such as the day of the week, paying bills and remembering names:

'I've got like Jane [daughter] and that particularly; she sort of keeps me genned up on anything I might have to pay or things like that.' (Gill)

'If I forgot a name and it was important I would apply to my husband and ask him to jog my memory.' (Hannah)

This effective strategy also had its difficulties, as carers pointed out that the women would forget and thus repeatedly ask the same question:

'She's very repetitive on some things, which is when I have to bite my tongue and say, "yes, yes, yes" all the time. It does get me down now and again trying.' (Anne's husband)

The reliance on family as a proxy memory was observed *in vivo*; for example Deirdre, who was interviewed in the presence of her daughter, would refer questions she could not answer to her. All the other women were interviewed alone and some wanted to leave the room to ask a family member about things that they could not remember, although I tried to reassure them that this was not necessary:

'I can't remember [how old she was when she married]. You could ask my husband, he probably remembers...I've forgotten [laughs]. I'll go and ask him, wait here.' (Hannah)

Telephone as a lifeline

For the women who lived alone the telephone was essential for maintaining contact with their family. Carers would telephone regularly to check that the women had remembered to do things:

'She just says, "Mum have you remembered this? Have you remembered to do that?"' (Deirdre)

'In the early morning before I go out Janice rings, you know, "Are you alright?" and I say, "Yes."' (Irene)

But the women's own use of the telephone was less effective as they would forget that they had already called their relative:

'Sometimes I phone Rita up two or three times and she says, "You've already phoned me, mum". I said, "Well I don't remember."' (Deirdre)

Her daughter described her mother's preoccupation with making sure she had telephone numbers at hand, indicating just how much the telephone had become a lifeline:

'Every time I come she asks me for the telephone numbers. So she keeps them all in her little purse in her bag.' (Deirdre's daughter)

Loss of family contact

Several women expressed some distress about a lack of contact with their families. Caroline described feeling lonely and this was also the dominant theme in her biographical account:

'I was left alone, you know. And then the children got married and now I am on my own [emphasis on the am, as in she really is on her own now]...I haven't got a husband and it's so lonely.' (Caroline)

Her granddaughter, who lived in the flat upstairs, explained that memory loss exacerbated feelings of loneliness as Caroline would forget that her children had visited and thus on the occasions that she was alone this was experienced as always being alone:

'We do get visits from the family, but there will be a day or a couple of days when she's on her own most of the day and she doesn't like that. Because she can't remember yesterday...she thinks that's the day every day, just sitting there and that's what makes her sad.' (Caroline's granddaughter)

Gill's loneliness was understandably attributed to the recent death of her husband:

'Well, I think [enjoys], nothing, nothing much really [laughs]. Well you know it's, what shall I say. I suppose 'cause I miss my husband...life gets a bit boring.' (Gill)

Anxiety about being alone was also present as a biographical theme:

'I was always a very nervous person and I never liked being on my own. I think even with my sisters, they were a bit like that...My mother was always nervous.' (Gill)

Brenda, although she lived with her daughter and her family, expressed a sense of loss of not having her extended family around her; there may be a cultural significance to this as she is of Southern European background. She wished she could appeal to an extended family to help her with her abusive son-in-law:

'We have nobody to help us, darling. Our family is not here...I have nobody [sighs].' (Brenda)

Hannah also experienced a sense of disconnection from her children, one of whom lived abroad. Contact with her other daughter was limited due to a difficult relationship with Hannah's husband:

'I don't see much of Jennifer...My husband and Jennifer don't have a terribly good relationship, which is a pity. Nothing to do with me whatsoever...I haven't seen her for ages, Jennifer.' (Hannah)

People cannot always be relied on

The women's dependence on their families for support also came with an acknowledgement that others could not necessarily be relied on to be there for them and that they at times had to face up to this:

'Obviously my son's at work and my daughters, well I've got Jane, but I can't, she's got a family so she can't always be here.' (Gill)

'So you have to make your own life, haven't you? You've gotta make your own life.' (Caroline)

Yet Caroline's account also illustrated the effect of cognitive impairment in depleting her capacity to make her own life:

'I don't know who's coming and I wait, sometimes they come, sometimes they don't come.' (Caroline)

The potential for conflict.

Conflict was a theme present in most of the women's accounts, and ranged from disagreements about their memory difficulties to reports of verbal and physical abuse. Anne, who described herself as stubborn, gave the following account of disagreements she might have with friends and family about her memory problems, where she would put up with it up to a point where she felt she needed to stand her ground:

'They say a thing and I say, "Oh yeah, alright" and that's it. But if I think it's wrong I don't; I'll tell 'em.' (Anne)

Deirdre relied mainly on her learning disabled son. Her daughter described how his limited capacity for patience could lead to conflict:

'James's coping mechanism, his coping mechanisms are not very good at the moment and he does shout at her a lot...She gets panicked and she shouts back. She gives him as good as she gets, but it winds her up.'
(Deirdre's daughter)

However, Deirdre's could also get into conflict with her daughter about plans to move her to a home, as observed in the following interaction:

Daughter: *'I think mum should be looked after better. In a, possibly in a home. Uhm, but mum is adamant that she will not go in a home. She will live and die here.'*

Deirdre: *'I'm not leaving this house. They've gotta take me outa here in me coffin.'*

Emma described how she tried to avoid conflict with her partner, but evidently this was not always possible:

'I like to listen to what he wants to listen to [on the radio]. I don't want to be battling with him anyway so let's have what he says is nice and I'll have it or I'll hate it as the case may be... How much longer are we going to be able to go on living together in harmony?... We disagree sometimes and I call him a silly old codger and he calls me a bloody little bitch and [laughs], we go on happily really.' (Emma)

Her partner described how Emma could become aggressive towards him and scream at him. He understood this as her frustration at her memory loss and anxiety about her security and connectedness. He admitted that at times he had felt so exasperated by this that he had hit her.

'I must admit it was so bad the other day, I simply couldn't stand it any longer and she wouldn't stop, she wouldn't stop. The only way I could stop her was slapping her face. Not very hard but I had to slap her face. Once or twice I smacked her bum. She becomes absolutely uncontrollable this gentle woman that you see here. Scares, and she's violent. She threatens me with her stick. And uhm, I don't know when it's going to happen. We can have a marvellous time during the day. Suddenly she changes.' (Emma's partner)

Conflict permeated Brenda's account and she defined her memory difficulties in terms of stress about verbal abuse from her son-in-law. The devastating impact of this experience to Brenda should be understood in the context of her dominant biographical theme: the importance of being kind to others. She described her past relationships with her work colleagues as follows:

'Oh I was very friendly, darling, with all the girls. I used to work and they love me very much. And if they do something I say to governor, no I do it. You know I make him not shout at them.' (Brenda)

She was acutely aware of the contrast in her past affiliation with others and her present predicament:

'Really no [she's not afraid of son-in-law], but I hate that. All my life everybody likes me.' (Brenda)

Although her daughter was very much aware of the situation, Brenda described how she tried to hide it from her:

'I don't want to tell my daughter, because she's got enough to worry, darling, I don't want to make it worse. Very, very, bad man... But my daughter she's working to pay, poor thing. So he's all day home and shout at me. I can't stand it, always shouting, that's why, that's it.' (Brenda)

Hannah also had a secret. She mentioned physical abuse from her husband, but then decided that she would rather not discuss this any further:

'This is a bit naughty, but my husband caused some of my aches and pains, but I won't go into that...He's okay now, but he was a bit awkward with me at one point...No, no, it's my little secret [laughs]. I don't want to spoil things for him, especially as he has a lot of friends and they come visiting and we have parties, so...No, no. I'd rather keep quiet on that.' (Hannah)

The possibility that Hannah might fear the consequences of reporting the abuse as a further threat to her connectedness echoes the experience of vulnerable people in general.

3.2.3. Friends and neighbours

This theme also fell on a continuum of connectedness and disconnectedness. Most of the women mentioned the importance they attached to maintaining contact with their friends and neighbours. These social contacts had a vital role in maintaining a sense of connectedness or affiliation:

'They [neighbours] always call out goodnight and that you know, something like that, yeah.' (Irene)

In Fiona's case the church was an important meeting point. She had been active in her local Catholic church for many years. Going to church was part of her routine, allowing her to participate as much as she felt able and thereby acting as an important source of continuity:

'Oh yes, lots of friends at church yeah, yes great they are. And the priests are lovely there as well.' (Fiona)

Friends and neighbours took on important practical tasks and this was particularly evident with those women whose main family carer did not live locally:

'Betty next door, she goes and pays me rent and that for me. She gets me pension and she pays out what the gas and the electric and bills what I have to pay. So, you know, that stops me forgetting.' (Deirdre)

However, some social contacts were not experienced as supportive. As mentioned above, Anne had a tendency to get into conflict with friends and family about the extent of her memory problems. Hannah reported difficulties in joining in with her husband's Turkish friends:

'The thing is that my husband is very, uh, a very sociable guy and he is forever entertaining [laughs]...The only thing that annoys me is that an awful lot of them are Turks!...So the house will be full of Turks. I've nothing against Turks [laughs], but I don't understand a word of their chatter.' (Hannah)

The family carers could also be instrumental in maintaining the woman's contact with her friends by recruiting them into the care routine. Irene's daughter had reached an agreement with her mother's friends to have her over for supper every evening:

'Jim and Doris have been absolutely marvellous. I mean not many people, I understand most friends drop people with Alzheimer's. Well there's never any indication of that with Jim and Doris. So she goes up. So you know it's difficult to look back but, but when this all happened, that sort of began to happen as a result of a discussion with me. She would go up every evening and have a snack up there and sit with them and watch the telly. Well that's still happening you see.' (Irene's daughter)

Hannah's husband arranged for one of her friends to come over and cook a meal with her when he needed to go out. He explained how he had arranged this surreptitiously, although Hannah in fact had already mentioned how much she valued this arrangement. He also mentioned the importance of Hannah and her friend cooking a meal together as a way of maintaining her skills:

'So I ask a lady friend of ours to come and stay with her. But I ask her to allow my wife to do the cooking and she does the supervision. So that she is active...But she doesn't know we have asked her. She doesn't know we have arranged it the way we have so that she is not left alone. She's a friend of ours. So she thinks she is just coming to visit, but in fact it is all organised.'
(Hannah's husband)

By contrast, despite the fact that she had lived in the same neighbourhood since childhood, Caroline appeared to have little or no social support from friends. She explained that she had always been very family-orientated and never really had friends:

'No, I never have done since I've been married. No I never go out with friends. I go out with relations, you know and that. I've been out with relations, but I don't have friends no.' (Caroline)

3.2.4. Social roles

This theme also fell on a continuum of connectedness and disconnectedness, as some women appeared to be effective in maintaining a sense of purpose, whilst other experienced a loss of social role. Related to the above theme 'Friends and neighbours', Irene had found an important social role in visiting her friend every evening. Although the daughter described this as part of Irene's care-package as the friend provided an evening meal, Irene felt that because her friend's husband was deaf she had an important responsibility in keeping her friend company:

'She finds it's nice to have someone like me to come up to her...I think she looks forward to me going up there so that she can chat to somebody, so yes [feels a sense of responsibility towards her friend].' (Irene)

The importance of being occupied and of hard work were important biographical themes in Fiona's account. She had worked as a cleaner in the past and now that her daughter went out to work she had an important role in doing the housework:

'I can do everything. I do washing clothes in the machine and things like that when she's at work, because she has to be at work all day you see, so that means I'm helping her out.' (Fiona)

Others felt that they were no longer able to actively participate in any responsibilities:

'I don't have no thing-me-jig [responsibilities]. I just wait and see the kids. I don't know how many I've got now [laughs].' (Caroline)

In contrast to Caroline's resignation, Brenda struggled with her loss of social role. Her biographical account pointed to strong maternal caring and protective values. Her concern about her daughter's marital difficulties appeared to fuel her battles with her son-in-law:

'Of course I worry about the future, my God, not for me. For me I don't care if I die tonight...I wish I see my daughter more happy, that's it, that's very important. She's not. I help her. That's what I wish, she's got a better life, you know.' (Brenda)

3.2.5. Familiarity

This theme describes the importance of the women's connectedness or familiarity with their environment. It demonstrates how a reliance on implicit memory, that is well-rehearsed skills and routines, helped the women overcome difficulties with episodic memory. The theme has two sub-themes: routines and staying local.

Routines

For some women the reliance on a regular routine was so effective that they did not experience memory loss as a problem:

'Well so long as I live a fairly regular life I don't have difficulties...There are certain things that reoccur regularly, that I do remember...Well I do things regularly and I do on the whole remember to do them.' (Emma)

'I don't think for daily purposes it makes a lot of difference, because I've been in this house for a long time. I do the same things everyday...He likes cooking and I do the clearing up afterward, and that is our regular routine.' (Hannah)

When asked whether she had any difficulty remembering where to put things whilst clearing up Hannah replied:

'Not at all, I do that automatically.' (Hannah)

However, her husband contradicted this when he expressed frustration about her difficulties with household routines:

'Mainly she insists to do certain things, but she always does them wrongly...When she puts the dishes in the washing machine she puts them all in the wrong places. And then she starts it without it being full. So she doubles the work and then when she brings the dishes out she doesn't know where to put them.' (Hannah's husband)

Anne's husband pointed out the consequences of upsetting a routine and changing the environment:

'We had a bit of a new kitchen fitted last year. It was a bit of an upset when we had it fitted. But things, like drawers and pots and pans have almost gone back to almost identical places. [laughs] But half the time I can't find anything if she gets out there...she cannot get into that routine.' (Anne's husband)

Irene explained that Alzheimer's disease did not interfere with her ability to carry out her daily routine. When asked whether she ever needed to write things down to remind her to do things she replied:

'No I can't say I write much down, no. See life runs too smooth really.' (Irene)

Her daughter had taken on what she described as a managerial role in structuring her mother's daily routine. This routine appeared to help the daughter to cope as much as it did Irene:

'I mean she's quite good at remembering, now that we've got into, you know at first it was a problem, but now we're into this strict routine... You see but that isn't a problem anymore, because we've got such a nice, everything's better, you know. I'm not so fraught and the structure's there so she can cope within the structure really well.' (Irene's daughter)

Other carers, whilst acknowledging the importance of routine, expressed concern about limited routines under-stimulating the women:

'She has a set little routine to her life and there isn't much to it to be quite honest. It's you know, during the week, Monday to Friday, it's going to church. She'll go to church everyday and possibly meet up with a friend or two down there and they might go and have a tea or a coffee afterwards. And then she'll come back home and uhm, watch TV or possibly go to bed. And that's really it, there isn't really much, there's no sort of activities or pastimes really.' (Fiona's daughter)

Staying local

Most of the women had lived in their local neighbourhood for many years and this familiarity kept them orientated to their environment and prevented them from getting lost:

'No not at all [does not lose her way], no I've lived here for so long.' (Gill)

Irene felt very secure in her local neighbourhood, where she had lived since her childhood:

'And that's how it's always been...So really I haven't known else than living over this way.' (Irene)

She lived alone, but despite her memory impairment and mobility problems she was quite active. When asked whether she ever felt worried about going out alone she replied:

'Some people have said that to me before, but I don't, well I've been living down this road for so many years...I've always found that it's been very easy...But I walk with a trolley, because me legs aren't all that good, so that quite suits me, yeah and I don't take a handbag or nothing. So I don't really get worried about it or nothing.' (Irene)

Staying local may also be seen as a protective strategy, where the women avoided going further afield for fear of getting lost:

'The only thing is I couldn't go far away. I wouldn't be able to go on my own far away...I might get lost, yes...I can only, I only go where I know where I can go. Any further than that I wouldn't be able to go...I get my pension, yes, 'cause it's just over the road; the Post Office is not far away.' (Fiona)

The availability of local amenities therefore played an important role in maintaining the women's independence. The absence of local supermarkets meant that most women relied on their families to shop with them or for them:

'The thing is now, we did have a supermarket up, just up the road there. So I used to go there. Well that's all closed up now. So you have to go over the hill to the other side and I don't particularly want, want to do it if you know what I mean.' (Gill)

3.3. PROTECTIVE STRATEGIES – IT'S NOT A PROBLEM

Three themes 'It's not so bad', 'Isn't it funny' and 'It's not really an issue' are described here as protective strategies whereby the women conveyed a sense that memory loss was not a problem. One interpretation of this is that such strategies were used to regulate feelings of embarrassment, humiliation and anxiety. Threats to the women's connectedness with the past, their environment and affiliation with or attachment to their families and friends may have motivated the women to underplay their difficulties by way of minimisation and avoidance. This is a tentative interpretation that should be balanced with the possibility that for some women the quality of their support meant that they did not experience memory loss as a problem.

3.3.1. It's not so bad

Most of the women gave some indication that their memory problems were not necessarily experienced as a problem. Some women offered evidence that their memory was not so bad, because they remembered the things that were important to them and things they forgot would eventually be remembered. This is described in the following two sub-themes.

Remembering the things that are important

In this sub-theme some women offered evidence that they had no real difficulties with their memory because they remembered the things that were important. The things that were important for them to remember were their family and their past, which supports the concept of connectedness as a valued aspect of self.

Anne insisted that she could still remember all her family's birthdays.

'I remember all their birthdays. I've got to.' (Anne)

This contrasted sharply with her husband's account:

'She's very repetitive on some things...especially birthdays, which birthdays are coming up.' (Anne's husband)

Her preoccupation with this may reflect the importance she attached to remaining connected to her family. She also attached some importance to being able to recount her life-story to her family:

'I mean I can go back. If they come round [family] and want to know anything and I tell 'em.' (Anne)

Brenda also explained that she never forgot things that were important to her:

'My memory's alright. I mean I talk about everything about the story of my life. I remember...Nothing special I never forget. All life, anything before now, how I say, to talk about things I don't forget.' (Brenda)

In the context of her current distress about her conflict with her son-in-law it was perhaps significant that she remembered being loved in the past:

'They really love me so very much, so many people there. I never forget.'

(Brenda)

Gill also talked about remembering her past and offered this as evidence that her memory was not so bad:

'I mean I can remember lots of so many things, like in my life. I mean I remember so many things, right from the past. I can go back to when I was about seven. I remember things. I can sort of see where we lived...I can remember so many things. I remember an awful lot about my life, incidents and everything.' (Gill)

It comes back

In this sub-theme the women acknowledged that they might forget things, but explained that this was not really a problem, as they would remember eventually or even straight away:

'I never forget really. Sometimes I forget little things, and then just quickly remember...I forget something for a moment, but after I remember alright. It's come back...Yes, yes, yes, straight away, yes.' (Brenda)

Anne explained that she might forget things if she was upset about something, but if she took her time it would come back:

'I suppose sometimes [has difficulty with memory], perhaps if I'm a bit upset, but if I sit and think then I can run back or whatever.' (Anne)

Caroline expressed relief when she did remember things. She seemed to benefit from the interview process as it allowed her to gradually remember the names of her children and gain a sense of achievement from this:

'Oh I've got the names of 'em! I did remember them [laughs as if relieved]...And you know, I got Bob, Rachel and Cathy. I know that. I do know I've got what I've got.' (Caroline)

It was difficult to establish whether the women were giving an accurate account of their difficulties. The extent to which they might be underplaying their problems often only became apparent in the carers' interviews, although it is possible that carers may have had their own motivations for portraying the women in this way. Brenda for example insisted that she had no difficulties when out shopping:

'Not really, no. And I never write down as well. I just go and buy what I want.'
(Brenda)

However her daughter's account suggested that Brenda was underplaying her difficulties:

'Shopping is a big issue for her, because she refuses still, I don't know if it is fair to say she refuses, but she actually forgets to make a list, which is kind of a Catch-22. She knows she needs to make a list to not get repeat buys, but she forgets to make that list. So when she gets back, all she's done is she's stocked up on the same items that she's already got. So I think shopping is really the main frustrating problem for her, which her memory loss affects that. I think it's the only thing really.' (Brenda's daughter)

Although Caroline's memory difficulties were now quite apparent, her granddaughter recounted an example from a time when she was still able to cover up her difficulties and the potentially serious consequences of this:

'We've had problems with a social worker, who wasn't aware of her, like the illness. And they asked her lots of questions and done a report...She thought fine, she could cope...And then when you looked at the report, 'cause she'd talked a really good story, she's done all these wonderful things, she got her own shopping and pension. Because she believes that's what she does, if you ask her. But obviously the truth is quite different. And that's the problem we've had, because she talks a very good talk sometimes and you really do believe that she's fine.' (Caroline's granddaughter)

Some of the carers thought the women underplayed or minimised their difficulties in the interview because of social embarrassment. Fiona was quite insistent that she had no real difficulties with her memory:

'To be quite honest I don't have any difficulties with my memory, no.' (Fiona)

Her daughter gave the following insight:

'I mean she is not very forthcoming when it comes to discussing her problem. I think she finds it quite upsetting when you do actually sort of refer to her memory problem and sometimes she doesn't want to talk about it really, because she knows there is nothing she can do about it and it frustrates her that she can't do anything about it...She doesn't really think there is much of a problem, it's just a frustrating problem for her. Uhm, but maybe that's just the way she deals with it...See this is a problem, I find I'm not 100% convinced that she tells me the truth a lot of the time. Not deliberately at all, but just, she'll say what she thinks I want to hear, rather than what actually is.' (Fiona's daughter)

Despite Irene's openness about her diagnosis, her daughter still felt that she underplayed her difficulties:

'She doesn't want people to know and she feels embarrassed, you know, frustrated by the whole thing.' (Irene's daughter)

In relation to the interview she informed me that:

'She thought you might be coming round to put her into a home.' (Irene's daughter)

3.3.2. Isn't it funny!

Humour as a theme in the interviews was often observed as the women appearing to laugh off their difficulties. This may be interpreted as a minimisation strategy for dealing with or covering up the humiliation and embarrassment of not remembering things:

'I do me hoovering I think I do, I don't know. I don't even Hoover! [laughing fit].' (Caroline)

'Isn't it funny! [laughs]. I should know my age; it sort of catches you. Is it a catch question?' (Gill)

Some carers also commented on this strategy. Brenda's daughter for example accurately mimicked her mother's response to such situations in the following interview extract:

Daughter: *'I think it distresses her when she forgets. She sometimes tries to turn it into a joke, but I can tell she's not happy about it.'*

Investigator: *'So when she forgets something she may joke or laugh it off. Is that what you're saying?'*

Daughter: *'Well, yes it's not so much with me or our immediate family, but maybe someone like yourself, it's, "Ha, ha, forgive me darling, I always forget!" something like that, you know.'*

Investigator: *'Yes, she can be very charming.'*

Daughter: [Laughs] *'Yeah, yeah, but I don't think she's happy and I think the quality of her home life is not what it should be and I think all of that is just making it worse for her.'*

Brenda acknowledged her laughter, but then pointed out that her situation really was not a laughing matter:

'Oh yes. [Laughs]. Yes, I laughing darling, but I hate people like that, but that's life, ain't it? It's terrible, ain't it? I don't know darling, what to do.'

(Brenda)

However, laughter in the interviews was not always a strategy for covering up embarrassment, and some of the women genuinely seemed to enjoy being interviewed. Caroline talked about her deep sense of loneliness, but when I pointed out that she had been laughing she replied:

'Yeah, 'cause it's a bit of fun ain't it!' (Caroline)

3.3.3. It's not really an issue

Whereas minimisation was a strategy by which the women sought to protect themselves from feelings of humiliation and embarrassment, avoiding the issue was a means by which both the women and their carers handled anxiety about the uncertainty of progressive cognitive impairment. It is illustrated by two sub-themes: 'Not thinking about it' and 'Not talking about it.'

Not thinking about it – one day at a time

This was a theme present in most of the women's accounts. It has both elements of acceptance and avoidance, or perhaps rather a sense of resignation that the women had little control over their situation. The focus was therefore on the present, as there was little point in worrying about the future:

'I don't worry about it, I mean I just go from day to day and I don't really even think about that [memory difficulties].' (Fiona)

Anne acknowledged this as a strategy to avoid disappointment:

'I take the days as they come and then should it fall back well then I'm not so disappointed either.' (Anne)

Irene attended a support group for people with Alzheimer's disease, and had large print literature about it in the house, yet she said she did not think about it:

'I haven't thought so much about this memory lark, because it hasn't really affected me. I don't really worry about it. I mean I don't make an effort to worry about it and that really at all...When I read about that, it doesn't worry me. I don't think a lot about it, because I don't seem to walk around the wrong way or anything like that, you know, that's what I think...Well I suppose I haven't thought about it really have I.' (Irene)

Her daughter appeared to mirror this coping strategy of not thinking about the future and focussing on the present:

'You know we work with this on a day at a time basis really. I don't think about the past and I don't think about the future, you know we just get on. You know I've structured a very interesting life, you know relatively interesting life for her, and uhm, she seems very happy.' (Irene's daughter)

However, she acknowledged that her mother did worry that she was "going daft", but tried not to think about this as it was upsetting:

'I mean I try not to think about it too much as I think it's rather, you know it's rather upsetting to think that she's sitting thinking all these things, but there can't be anything worse than feeling your brain is in turmoil can there, because of the sort of lack of control. It must be a ghastly thing to be going through. So it's yeah, I try not to analyse it too much.' (Irene's daughter)

Not talking about it

Not talking about memory problems appeared to be a strategy used by professionals and carers, as well as the women themselves, as a means to avoid the communication of potentially distressing information. Some women were relieved that carers did not confront them about their memory difficulties:

'She [daughter] doesn't take any notice really.' (Fiona).

Similarly, by not talking about it Hannah thought others had not noticed:

'Well the children didn't notice anything.' (Hannah)

However, her husband confirmed he had in fact informed both their daughters that she had Alzheimer's disease.

One consequence of professionals and carers not talking about the problem was that it did leave some women wondering just what was said behind their back:

'I've no idea. They [memory clinic] don't say anything, not as far as I know, not unless they say anything to my daughter. I should hear. Touch wood I still got good hearing.' (Anne)

This avoidance of communication had the potential for creating confusion about who knew what. Gill's daughter was uncertain whether her mother had Alzheimer's disease, but preferred anyway to refer to her mother's difficulties as memory problems:

'I wouldn't like my mother to think she's going to deteriorate that badly. And so I just say to her, well you do have a memory problem, so we stick at the word, just we use the word memory, than the word dementia or Alzheimer's.'

(Gill's daughter)

Yet the researcher noted that at the informal visit Gill's other daughter did in fact refer to Alzheimer's disease in front of her mother. This type of open secret conveys a sense of stigma.

Carers mentioned the stigma of mental health problems and their own fears as reasons for not talking about Alzheimer's disease:

'I mean it disturbs her when she gets the letters from the memory clinic, because it says Mental Authority [Mental Health Trust] or something. She says, "What's this business about mental?" [laughs] Oh we do have a laugh about it, but she says, "I hope the Post Office doesn't think I'm mental"...And it does make me a little bit panicky uhm, if it was hereditary. I find it frightening and I suppose maybe I'm trying not to frighten my mum, because it's frightening me.' (Gill's daughter)

3.4. ACCEPTANCE – GETTING ON THE BEST YOU CAN

The women's acceptance of their situation was demonstrated by a number of strategies that fell into three main themes: 'Just put up with it', 'Normalising' and 'Problem solving'. Together these conveyed a sense of adjustment, or 'Getting on the best you can.' Whereas today's society may devalue acceptance as a passive strategy, I found that the women's acceptance of their situation had a sense of resilience that was echoed in some of their biographical themes. Most of the women described their background as working class, and their life-stories contained themes about not having much choice as life was hard, but some were also able to reconcile themselves to this by reflecting that they had been relatively fortunate:

'Don't forget you were really lucky to get a job, 'cause things were, you know, very hard really in those days...Although I suppose I thought after I could perhaps have done something better [than dressmaking], but then it didn't matter you know. You had to really. I mean, well times were hard in them days and you had to...I've never really wanted for nothing, wished I'd anything different really...I suppose I didn't do too bad.' (Irene)

Anne's husband gave a similar account:

'We didn't have any great ambitions. I mean I think then a lot us from our own background, we hadn't been, what would you say, brought up to have great ambitions. Just a normal run of the mill life, happy.' (Anne's husband)

3.4.1. Just put up with it

Acceptance in some of the women was evident from their use of a number of self-statements or cognitive strategies that helped to regulate their mood. They thus told themselves to accept their situation and to get on the best they could:

'Well it's one of them things ain't it in life. You just put up with it and you get on the way the best you can.' (Deirdre)

Some re-assured themselves that they had become used to it and could manage:

'I've adjusted to it. You know, I mean that's the way it is...Somehow I manage. I mean I don't feel distressed about it...I've got used to it now [laughs].' (Hannah)

The women's ability to reconcile themselves to their difficulties may well have been promoted by a sense of connectedness that allowed them to accept their dependence on their family. However, the way that the family handled this was important. For example, I experienced Anne as quite a strong dominant character, who admitted:

'I'm afraid I'm very awkward.' (Anne)

Indeed she attributed this characteristic to her background as a union representative, yet curiously in terms of accepting help from her family she said:

'I consider myself placid.' (Anne)

Acceptance for Anne was conditional. She stood her ground, putting up with her difficulties up to the point when others confronted her with her memory problems. Her husband managed such potential conflict by *"going along with her a bit"*, which he said the memory clinic had advised him to do. It would have been interesting to

explore in what contexts Anne felt the need to stand her ground, as this might have given some insight as to her personal priorities and values.

3.4.2. Normalising

This theme is an integral part of the women's acceptance of forgetfulness as part of normal ageing. This is illustrated by two sub-themes: accepting that forgetting details of things that happened a long time ago was normal, and comparing self with others who also had difficulties.

That was a long time ago

The first part of the interviews focused on the women's past. Although most of the women were able to give a good overall account of the important events in their lives, the impact of Alzheimer's disease was noticed in terms of disorientation in time, that is knowing when things happened and the relationship of the events in time. When confronted with this the women tended to normalise their difficulty in remembering in terms of the events happening a long time ago:

'Ooh! That was a long time [when she met her husband]. Oh I forget what day it was, what dates.' (Irene)

Fiona applied this same explanation to forgetting details about her childhood right through to those that happened only several months ago:

'It's a bit too far back to remember that now [her hopes as a young woman, laughs].'

'I can't really tell you. It is a long time ago [when parents died].'

'It's a long time back, now this is [death of husband, stresses the word long].'

'I can't remember that, now, that's quite a while now since she [psychiatrist] interviewed me.' (Fiona)

Others have difficulties too

Forgetfulness in old age might be expected and accepted as normal if the women had experience of other people who also had memory problems. Emma for example knew that her relatives had memory problems, as did her friends, and her partner also forgot things. What these people had in common was old age. She did not know she had Alzheimer's disease and thus made sense of her difficulties in terms of normal ageing:

'My uncles and aunts and grandmother had found it more and more difficult to remember things and people.'

'As I grow older I feel more and more of my acquaintances, so far as I have any, don't remember.'

'And he [partner] forgot to buy any more sugar this week and that sort of thing [laughs].' (Emma)

Deirdre considered herself lucky in comparison with others she knew had memory problems:

'It's alright though. I'm alright; I'm luckier than a lot of people...Well there's quite a few people worse than me, 'cause when I went up to the clinic the other day there was a lady there and she was a lot worse than me with her memory. And I thought to meself, "Well I am lucky."' (Deirdre)

Irene had the opportunity to compare herself to others by attending a support group for people with early-stage Alzheimer's disease. She also considered herself to be better off than others:

'I mean I don't forget nothing. You know when you hear people say, "Ooh I've forgotten to do that!" I've never felt like that, no.' (Irene)

3.4.3. Problem solving

This theme refers to various practical strategies the women used to compensate for their difficulties. To some extent the effective use of such strategies was dependent on an acceptance that the women had problems with their memory:

'I mean I don't like it, but I think you compensate.' (Gill)

The most common practical strategies in the women's accounts included staying active by doing things, writing things down, keeping things to hand, checking and taking medication.

Staying occupied

This sub-theme is presented as a continuum, where some women were able to stay active, whilst others were inactive and described themselves as 'bored'. Staying occupied was a strategy that offered some distraction from social isolation. For some this meant going out or watching television, whilst for others it involved engaging in previously valued activities:

'Always just get on and do things. If I feel like going up and doing my machining, I go and do my machining.' (Anne)

This approach contrasted sharply with that of other women who described their inactivity and disengagement from previously valued activities as a normal part of ageing, as discussed above.

For some the television filled the gap left by a lack of meaningful activity and social isolation. Caroline's response to a question about how she spent her days was:

'Nothing, I only sit and look at television...I do have the telly, but I don't see much of my family.' (Caroline)

Some women appeared to have few other activities apart from television. Fiona kept her television on during the interview with the sound mute. Almost automatically she switched the sound back on again as the interview ended. Deirdre was virtually

housebound. Neither she nor her learning disabled son were able to maintain the house. Apart from an old sofa with torn covers, the television was the only other piece of furniture occupying the centre of the living room:

'Well I like watching the telly now, cause I can't get out a lot. I used to like going dancing and things like that. I can't do it now, so what I do now is, I sit here and I watch me telly...If it's something I like. If it's not anything any good I turn up to the other side and watch it [laughs]' (Deirdre)

Some carers voiced their concern about just how much time the women spent passively absorbing the television:

'I don't know if she enjoys doing anything quite frankly. The only activity she does, which is a little bit of a concern to me is that she will be quite happy to switch the TV on from about nine o'clock and watch it till ten-thirty/eleven o'clock at night. And that television is on all day. It might be switched off now and then for a bit of a rest for an hour or whatever, but it is on. And she'll sit there looking at it and I sometimes wonder whether she is actually registering anything. It concerns me because she is not actually doing anything with her mind to keep it active.' (Brenda's daughter)

By contrast two of the women thought that watching television was a meaningful activity that helped keep their mind active:

'I like the programmes where they ask questions and like that, to see if I can answer 'em...Quizzes and that, yes. I do like them 'cause I can see if I can remember to answer them. I mean I miss a few of 'em, but I can I remember quite a few of 'em.' (Deirdre)

'Well, I watch the telly, which to me is interesting, 'cause you get a lot of things there don't you. I remember things off the telly sometimes, 'cause I

said to Janice, so and so and so and so. She says, "Where did you hear that?" I says, "On the telly." So I still do remember things like that.' (Irene)

In fact Irene watched relatively little television, and given the busy daily schedules organised by her daughter it was difficult to fit much more into her day:

'I come back about half past nine I suppose and then I'll just sit and watch the telly for a little while and then that's it.' (Irene)

The ability to stay active and engage in meaningful tasks therefore depended very much on the involvement of carers in structuring a routine. Attending day centres was an important part of most of the women's routine that kept them occupied:

'Well it's a change; it makes you feel different, don't it. You're seeing somebody and you've been somewhere. But when you're in here [home] you do nothing [laughs].' (Caroline)

Yet other women found attending a day centre less stimulating:

'Just sit there and do nothing [day centre]. Boring [laughs].' (Deirdre)

Interestingly for Fiona, a devout Catholic, going to church each day served a similar role to that of going to a day centre for the other women:

'Yes, oh yes. It's very good for you yes [going to church]. You feel like you're doing something.' (Fiona)

Writing a few things down

The practical strategy of writing things down was employed by most of the women; however upon further enquiry this appeared often to be a memory strategy that they had always used:

'I suppose if I had something I had to pay or this sort of thing, yes. Always write shopping lists, I always have [laughs].' (Gill)

Gill's daughter confirmed that her mother had always made shopping lists, but now she observed some problems in her ability to make the list and use it:

'She'll go to the fridge and say, "Oh do I need so and so?" and then she come back and write it down and a little while later she'll say, "I wonder if I need any eggs?" and she'll go off and look in the fridge. And she'll forget that she'd gone there a few minutes ago to look if she had any eggs. So, and it's no good getting annoyed or anything, you just sort of need to let her do it. And then we go shopping she'll say, "I haven't brought a list." And I'll say, "Yes you have mum, it's in your bag." "Have I?" So she gets it out and puts it away again and a few minutes later she'd say, "I didn't bring the list did I?" And I'd say, "Yes you did mum it's in your bag."' (Gill's daughter)

Post-it notes were also observed in Gill's house, reminding her to switch off the outside lights.

Hannah did not write things down to remind her, but thought it was a good strategy that she had not got round to using yet:

'I should really write some of the names down. I've been meaning to do that and I've never sort of got round to it. I'm thinking about people who come and go. I think if I wrote down the names. I should do that really. I've just never sort of got round to doing that, but I think it's a good idea.' (Hannah)

Keeping things to hand

This strategy was observed in several women and most vividly with Deirdre who kept important possessions such as telephone numbers and medication in a plastic carrier bag in which she would from time to time rummage during the interview:

'I've got some tablets [rummages around in her carrier bag] somewhere. Where have I put them?' (Deirdre)

Her daughter commented that this strategy was not particularly successful as things still went missing:

'Everything is in one bag, but they still go missing, so I don't know where they go.' (Deirdre's daughter)

Gill used a similar, but less extreme version of this strategy. Pointing to some bills in front of her on the coffee-table she commented:

'I think I sort of keep them handy.' (Gill)

Checking

This practical strategy was mentioned by two of the women:

'You've just got to make sure you've got everything all right [around the house]...I always make sure [the iron is off]' (Fiona)

'Like, did I buy milk today; I'll have a look in the fridge [laughs].' (Brenda)

However, checking could become a repetitive behaviour as the women might forget that they had already engaged in it. Examples of this are Gill's rechecking of the fridge as she made her shopping list as mentioned above, Deirdre's regular bouts of rummaging in her carrier bag, and some of the women's repetitive questioning.

Using medication

Seven of the women were receiving donepezil, an acetylcholinesterase-inhibitor. The use of acetylcholinesterase-inhibitors can potentially be interpreted as a practical coping strategy that may help people with dementia adjust to their diagnosis. However this requires a certain level of engagement of the women with their treatment. The level at which they were engaged in their treatment varied from being able to name Aricept (donepezil) and make use of dosage pill-boxes, to not remembering whether they actually took the medication which was administered by carers.

The way the women viewed their medication appeared to mirror their conceptualisation of their difficulties. Irene for example was the only woman who mentioned Alzheimer's disease in the interview and also the only one that could name the medication:

'Aricept I think, but I think there's something else I take...Well I'm not sure really, [what Aricept does] well I know I take it every day. I suppose it keeps me on an even keel, I don't know, but it seems to suit me if that's anything to go by, yeah. I never feel sickified or nothing like that.' (Irene)

Fiona, who attributed her memory problems to a fall, acknowledged that she used to have memory problems, but this had much improved since taking medication:

'For a while I did [have memory difficulties] yeah, but then they started giving me memory tablets...They give you memory tablets now you see. And after that then it was much more helpful [laughs]...Now they have done me a lot of good I must say.' (Fiona)

Deirdre conceptualised her memory problems in terms of normal ageing and complained of headaches and fainting spells. She thus gave the following account of why she took donepezil:

'It's supposed to be to help me headaches and me passing out.' (Deirdre)

Brenda's daughter wondered whether her mother might have 'senile dementia' or Alzheimer's disease. She had sought a referral from her GP as she had read about medication. This may explain why, although Brenda was still waiting to receive her diagnosis, she seemed to be aware that medication existed. She conceptualised her difficulties in terms of worry:

[The doctor said] *"There's nothing I can give you to get you to remember. No, better not."* How I take medicine for nothing and maybe I make myself worse, ain't it? I dread to take it. I try to be alright.' (Brenda)

Anne did not know why she was taking donepezil, but was not worried about this as she was happy to leave this up to her daughter:

'I don't know. No, I don't ask, I leave the medicines to my daughter.' (Anne)

She also described using a pill-box alarm:

'I've got a little white tablet I take. It's in here...[picks up a pill-box with time alarm. Opens AM box] Oh, she's got to refill it. [Opens PM box] That's the one.' (Anne)

Caroline was no longer aware that she received medication, which was administered by her granddaughter, who had taken control over this because in the past Caroline had forgotten that she had already taken her tablets and would take multiple doses:

'That's why I give it to her now. Because she made herself quite ill, because she took them all at one time. Because she couldn't remember that she took 'em, so she took 'em again.' (Caroline's granddaughter)

3.5. A LEVEL OF CONNECTEDNESS MODEL

The results presented in this chapter show how the women acknowledged to a greater or lesser extent that they had difficulties with their memory, for which they gave various explanations. Eleven themes grouped into three higher-order themes of Connectedness, Protective Strategies and Acceptance describe how the women experienced memory problems and attempted to manage their difficulties. Figure 2 (p.115) gives an overview of these results, which is presented as a Level of Connectedness Model of the women's appraisal and coping processes. Qualitative

research cannot claim to identify predictors or correlations, thus the connections made between the higher-order themes are tentative interpretations represented by dotted lines.

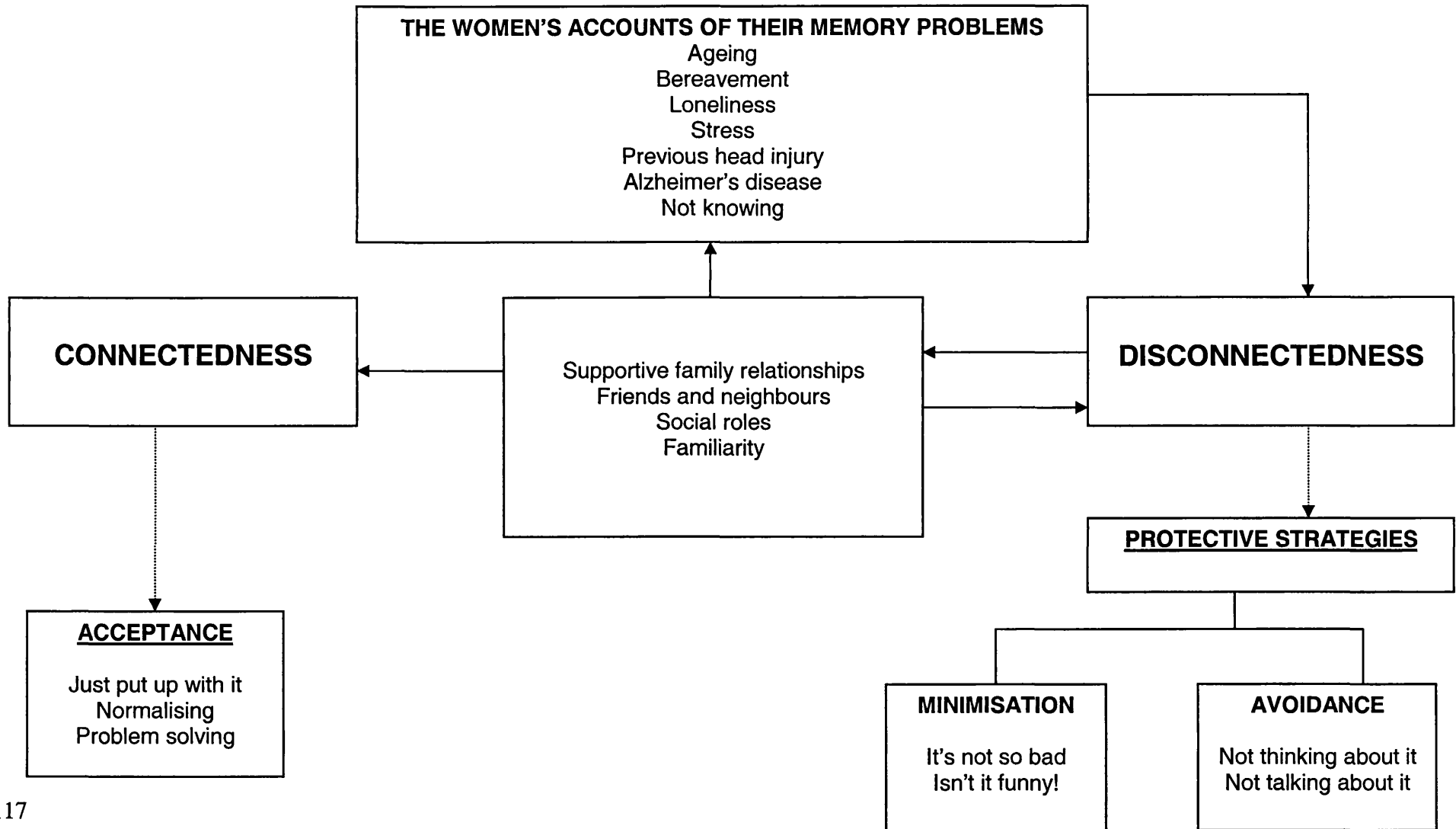
The higher-order theme of Connectedness relates to identity or sense of self, derived from attachment to family and friends, affiliation with social roles, familiarity with surroundings and a sense of continuity with the past. Memory loss was experienced as a threat to the women's identity. The model thus shows a tension between disconnection and coping strategies that relied on maintaining a connection with others and the environment. Thus the level at which the women were connected with family, friends, social roles and their environment may counterbalance or exacerbate the disconnecting impact of cognitive decline. This places coping in an interpersonal framework, where the ability of the women to maintain a sense of self is inherently dependent on the readiness of others to facilitate connectedness.

A cyclical process may exist whereby the support network maintains the woman's account of her memory problems. For example, in one case, family, friends and professional support actively engaged the woman in acknowledging that she had Alzheimer's disease. Although she may continue to experience Alzheimer's disease as a threat to her connectedness, it is proposed that the support she received lessened the stigma of the diagnosis and facilitated acceptance. The other women's accounts of their memory problems were left unchallenged, either because the carers themselves were not aware of the diagnosis or chose not to discuss it. Thus the women's appraisal of their difficulties may in part be dependent on the signals they receive from others that may encourage or discourage them from talking about their difficulties.

As discussed above the women's acceptance of their memory problems is likely be related to previous coping styles, cultural values of resilience ('Getting on the best you can') or a resignation that they had little control over their situation and therefore had no choice but to accept their difficulties. However, it is proposed here that the women's level of connectedness in terms of their attachment to family and friends, continuity of social roles and familiarity with their environment may facilitate acceptance and the effective use of problem solving strategies.

Threats to connectedness promoted protective strategies whereby the women dealt with the embarrassment and humiliation of memory loss by way of minimisation or covering-up strategies, including the use of humour. Anxiety about the progressive degenerative nature and stigma of dementia led to avoidance strategies employed by the women as well as the carers and professionals. This interpretation needs to be balanced with the possibility that the level of support some of the women received may effectively have minimised the impact of cognitive impairment on their ability to function in their day-to-day living.

Figure 2. A Level of Connectedness Model of the appraisal and coping processes of women with early-stage Alzheimer's disease.



DISCUSSION

This study examined the appraisal and coping processes of women with early-stage Alzheimer's disease. Semi-structured interviews were conducted with nine women and their partners or carers. As this was a qualitative study, the aim was to understand and represent the women's perspectives. The study was introduced as research into coping with memory problems. Not all the women had been informed of their diagnosis. They gave various accounts for their difficulties including ageing, social isolation, bereavement, stress, previous head injury and Alzheimer's disease. The study thus shows how the women actively sought to make sense of their difficulties.

The interviews were audio-taped, transcribed and analysed using Interpretative Phenomenological Analysis. This generated eleven themes relating to how the women understood and managed their difficulties. The themes are grouped into three higher-order themes of Connectedness, Protective Strategies and Acceptance. These are presented in a Level of Connectedness Model. Memory problems were experienced as a threat to connectedness or sense of self, derived from attachment to family and friends, affiliation with social roles, familiarity with surroundings and a sense of continuity with the past. Threats to the women's connectedness may have motivated them to use protective strategies to underplay their difficulties by way of minimisation and avoidance, thus conveying a sense that memory loss was not a problem. It is proposed here that higher levels of connectedness in terms of the women's attachment to family and friends, continuity of social roles and familiarity with their environment may facilitate acceptance and the effective use of problem solving strategies.

4.1. WOMEN COPING WITH EARLY-STAGE ALZHEIMER'S DISEASE

The review of the literature presented in Chapter 1 has shown that people with dementia are active agents in maintaining a sense of self. This study investigated how this applies to women with early-stage Alzheimer's disease. The results are discussed in this chapter with reference to psychological theories, models of coping with chronic illness, previous qualitative research in coping with dementia and possible gender differences in coping. This is followed by a consideration of methodological issues, areas for further research and clinical implications.

4.1.1. The social psychology of Alzheimer's disease

The interviews with the women and their carers illustrate aspects of the social psychology of Alzheimer's disease, where its manifestation and progression depends on the interplay between neurological impairment, personality, biography, physical health, and social psychology (Kitwood, 1997). The women's personality and biography provided a repertoire of behaviour acquired through experience that may have affected their appraisals and coping styles. Most of the women described their background as working class and their life-stories contained themes about not having much choice, as life was hard. This may have predisposed some to using acceptance as a coping style, perhaps based on cultural values of resilience. For example, Deirdre's daughter described a consistency in her mother's approach to past and present adversity. Her response to heart disease and cancer earlier in life was *"just to get on with things"*, leaving the family to do the worrying. This description of her past coping appeared also to apply to the present situation (e.g. *"you get on the best you can"*).

An important theme in this study was that of the women's familiarity or connectedness with the environment. It was striking that most of the women still lived in the neighbourhood where they were born. This familiarity with their

environment to some extent protected the women from disorientation, allowing them to rely on routines and make use of local amenities. Changes to the environment had a considerable impact in terms of disorientation and social isolation. Social withdrawal in dementia is often attributed to an inability to participate due to cognitive impairment, but may also be a consequence of the person's physical health. Notable in this study were the detrimental effects of frailty, immobility and vulnerability in cold weather in disconnecting the women from their environment.

Malignant social psychology is demonstrated in this study by the reports of physical and verbal abuse. The importance of being kind to others was the dominant biographical theme in Brenda's narrative and she accounted for her memory problems in terms of the stress caused by verbal abuse and conflictual family relationships. Of interest is that some carers were very much aware of the detrimental effects of this, but appeared helpless in stopping conflictual dynamics. Malignant social psychology may arguable be a product or symptom of carer strain. Certainly the carers' interviews revealed high levels of distress.

According to Kitwood (1997), weak 'inner-stabilisers' make the person with dementia extremely susceptible to the impact of social psychological processes. The value that the women in this study attached to social support points to its role as a factor in counterbalancing this. Kitwood described how interactions with others will influence the way a person responds to the onset and progression of dementia. This is echoed in the current study where the ability of the women to maintain a sense of self was dependent on the readiness of others to facilitate connectedness, which places coping in an interpersonal framework.

4.1.2. Attachment theory

Dementia may be experienced as a gradual loss of security. In this context, striving for connectedness resonates with attachment theory (Ainsworth, Blehar, Waters, & Wall, 1978; Bowlby, 1979). The formation of attachment bonds with others creates a safety net, which is thought to be particularly important in early childhood in providing a sense of security that allows the child to explore the environment. The quality of early attachment experience is thought to be internalised in the form of a working model of close relationships throughout life. The loss of significant others will have an impact on well-being at any age, however the person may be able to draw on internal representations of past secure attachments to provide self-reassurance. McCarthy and Davies (2003) describe how attachment related issues of children evacuated during the Second World War continue to exert an influence on psychological well-being in later life as older people may be confronted with increasing levels of insecurity. Kitwood (1997) points out that in dementia the need for attachment is particularly strong, as the person faces uncertainties and memories of past secure attachments may be lost.

The term Connectedness is used as a label for a higher-order theme in this study because it goes beyond a striving for attachment to friends and family to incorporate affiliation with social roles, familiarity with surroundings and a sense of continuity with the past. Dementia poses a challenge to all these aspects of connectedness. Some women appeared to be effective in maintaining a sense of purpose, whilst other experienced a loss of social role. The women's connectedness or familiarity with their environment allowed some to engage in well-rehearsed skills and routines, which may have helped them overcome difficulties with episodic memory. Most women reported that they could still remember the important things about their family and their past, whilst some appeared to be distressed by their difficulty in remembering. It is likely that the ability of the women to retain a sense of

connectedness was to a large extent dependent on others to facilitate this. The distinction between Connectedness and the theoretical concept of attachment also serves to emphasise that the interpretation of the data was not driven by attachment theory, but similarities were noted post analysis.

Miesen (1992, 1993) interpreted the behaviour of people with dementia in terms of attachment theory. His work was influenced by the observation that some people with dementia referred to their dead parents as if they were still alive (Coleman, 1986). This is interpreted as an expression of an emotional need for security. Other behaviours such as inactivity are understood as insecurity and reluctance to explore an unfamiliar environment. Aggression is interpreted as a possible reaction to threats to attachment.

Attachment theory in dementia care has mainly been applied to people in the later stages of cognitive impairment, providing a framework for understanding the threats to a person's security when faced with residential care (Cheston & Bender, 1999a). What this study highlights is that a concern about attachment is an issue from the earliest stages of dementia. Fearfulness related to insecurity may lead to attachment behaviours such as shadowing carers, becoming distressed when carers leave and seeking reassurance by asking repetitive questions. A decline in a person's cognitive abilities makes it harder for them to 'hold on to' their attachment figures when they are not physically present. In this study this was most vividly evident in Caroline as she tried to remember the names of her children. She was unable to remember whether people had visited, contributing to her sense of perpetual loneliness.

4.1.3. Narratives and self-identity in older women

The interviews allowed the women to reminisce about their childhood, family, occupation, interests and losses. The importance of the women's biographical accounts for understanding the impact of Alzheimer's disease was apparent in each individual account. The presentation of individual case studies goes beyond the scope of this study; however the richness of the accounts would have made this possible.

Narrative theory proposes that people actively create and reconstruct stories about themselves that help them to retain and validate their self-identities (Kaufman, 1986; Middleton & Edwards, 1990). As discussed in Chapter 1, neurological impairment makes it more difficult to retain self-identity and the person requires help from others to maintain their personhood and sense of self (Kitwood, 1997; Sabat & Harré, 1992; Sabat, 1994, 2001).

Middleton and Edwards (1990) emphasise the importance of focusing on the function of memories rather than the accuracy of the account. They propose that memory has a function of providing a narrative that helps the person make sense of her life and communicate with others. Thus when people are asked to talk about their past, they give an account of themselves as social beings. The emphasis and meaning they generate in their accounts are likely to be influenced by current concerns. Two of the women's narratives were dominated by a sense of loneliness. Both these women were widowed. For Caroline loneliness was a consistent theme in her description of her past, the present and her account of her memory problems. She seemed to reconstruct her past in terms of loneliness. Such consistency in her biographical narratives may be created by her interpretation of her past in terms of her current concerns about her connectedness.

According to Kaufman (1986) people retain a sense of self in recounting their life stories in terms of key elements or values that are important to them. Cheston (1996) described how people with dementia recreate their past as an active coping strategy to overcome feelings of being useless and to enable them to make sense of the world. It may be assumed that the women drew on memories to construct stories about themselves that allowed them to validate their self-identity. This is done within the context of the norms and cultural values that have shaped these women's lives. For example, Brenda was born and brought up in Southern Europe. Her father was a wealthy man who appears to have been an important benefactor to the community. This may well explain the strong values she had about helping others. She told how as a child she helped the other girls at school. She went on to help "the girls" she worked with in a factory. Brenda and her husband later helped other people from their country of origin to settle in London. Helping others was clearly a valued social role and this was the self that Brenda wanted to show me. Her distress may be attributed to a deep sense of loss in not being able to fulfil this role now. The daughter described how Brenda was unable to "let go" of her as an adult. She had become involved in her daughter's marital conflict and was still trying to fulfil her role as a protective mother.

In examining the narratives of two older American women, one of whom had Alzheimer's disease, Shenk *et al.* (2002) found that themes in both narratives were similar in that they were consistent with gender-based, working class, rural American cultural values including closeness of family, hard work, ties to the land, and religious faith. The women in the present study lived in inner London and suburban Essex. Their biographical themes included acceptance and resilience in terms of not having had much choice in life, hardship in making ends meet, but also a consideration that things had not been too bad. Connectedness also featured as a biographical theme in terms of the closeness to family, the experience of loss, being

alone and being good to others. Most of the women had a long working history, and enjoyment and pride in work also featured as an important biographical theme.

What therefore seemed to be different about the women in the present study and those in the American study was that the British women did not for the most part appear to rely on religious faith. This may highlight an important cultural difference, but I also acknowledge that I was perhaps less attuned to the women's spirituality. Fiona did talk of the importance of her Catholic faith, which I explored in terms of going to church as being a valued activity, ignoring the way that her faith might have helped her cope. There was a difficult impasse in the interview as she directly questioned me about my beliefs, and my admission of a lack of faith may have contributed to her reticence in discussing her memory problems.

What is striking about the narrative accounts of the widows is the absence of reference to their husbands. This may be a feature of neurological impairment in Alzheimer's disease, where a distant past and current concerns are remembered, but a large 'middle portion' of life appears to be absent. This was observed in most of the women's accounts, although it should be acknowledged that my questioning and the structure of the interview schedules could equally account for this. It is also possible that the absence of late husbands in the women's narratives may be a product of avoidance as a way of coping with loss, perhaps mirroring the protective themes of 'Not talking about it' and 'Not thinking about it'. This is most striking in Emma's life-story who described the importance of family relationships, yet her closest relationship (according to her partner) in the form of her sister, who had recently died, was completely absent. Irene's daughter also noted that her mother rarely talked about her late husband, but gave a different insight as to why this might be so by suggesting that she was happier without him as their relationship had been

conflictual. This serves as a poignant reminder that the attachment histories of individuals are variable.

4.1.4. Coping with chronic illness

Maes *et al.* (1996) considered coping with chronic illness within the context of the individual's social environment, life goals and values. It may be useful to reflect on how the model presented in Figure 1 (p.21) can be applied to data from the women's interviews. Demographic characteristics such as ageing, and life events such as bereavement and other illnesses were appraised together with memory problems as placing demands on the women. This combined experience of loss accounts for the women's concerns about their connectedness. In the face of lowered internal resources such as physical strength and energy in ageing, and the impact of neurological impairment, the women came to rely more on external resources such as social support to facilitate coping.

Coping refers to a person's cognitive and behavioural efforts to manage demands. In this study the women appeared to attempt to manage the effects of memory problems by way of striving to maintain their connectedness to family, friends, social roles and their environment, as well as problem solving, acceptance, normalisation, minimisation and avoidance strategies. These categories appear to coincide with the concepts of problem-focused and emotion-focused coping (Lazarus & Folkman, 1984). It may be argued that the women's striving to maintain their connectedness, as well as problem solving tasks such as writing things down and taking medication, fall into this category of problem-focused coping. However this is misleading, as there was little sense of the women independently taking direct action to initiate such strategies. Striving for connectedness was not so much an action that the women could perform, as a valued aspect of their sense of self that was dependent on an interpersonal domain.

This supports the work of DeLongis and O'Brien (1990) on the role of interpersonal factors in determining a number of aspects of coping in ageing families. In examining coping in carers, they presented the notion of relationship-focused coping (a form of coping directed at maintaining and regulating social relationships) alongside emotion- and problem-focused coping. This highlights the importance of connectedness as an important coping strategy for dealing with adversity. However, for the women with dementia, connectedness was as much the problem as it was the solution. Memory problems were experienced as a threat to connectedness and their ability to maintain a sense of connectedness was largely dependent on their carers.

The higher-order theme of Acceptance at first glance appears to resonate with the findings of Kiyak (1988). Acceptance was the main coping strategy endorsed by people with Alzheimer's disease and their carers in Kiyak's questionnaire study. Kiyak identified acceptance as a separate coping strategy alongside problem-focused and emotion-focused coping, and hopefulness. It is described as a passive strategy adopted in the face of the chronic and irreversible nature of Alzheimer's disease. Previous qualitative research (Gillies, 2000) similarly reported the most common coping strategy to be that of resignation: an acceptance of circumstances that were perceived to be beyond the person's control. In the present study the higher-order theme of Acceptance is not seen as a passive strategy; the women's acceptance of their situation had a sense of resilience that was echoed in some of their biographical themes as discussed above. It incorporates themes that relate to both problem-focused and emotion-focused coping, giving a sense of the women making the best of their situation or 'Getting on the best you can.' This study would therefore agree with the assertion by Kiyak that acceptance is an effective form of functional coping with cognitive decline. However, it is proposed that the ability of the women to accept their situation is a product of previous coping styles and

cultural values of resilience, which is also mediated by a level of connectedness that allows the women to accept their situation.

In her review of research on how people experience illness, Charmaz (2000) notes several common themes: ambiguity and uncertainty, autonomy and control, stigma and shame, isolation and connection, and loss and reconstruction of self. These resonate with the data from the interviews with the women and their carers in this study: not knowing, reliance on others, social isolation, concerns about connectedness and loss. The presence of stigma was more evident in the carers' accounts that described the women's embarrassment and humiliation. The effect of stigma is likely to be that of encouraging the women to hide their difficulties, using protective strategies such as minimisation and avoidance. The part that carers and professionals play in not talking about dementia confirms this sense of stigma.

A reconstruction of the self is less evident in this study, as the women appeared to be holding onto, or maintaining their sense of self by way of striving for connectedness. This concurs more with Charmaz' concept of a Salvaged Self, an identity based on some valued activity or attribute the person is able to maintain despite illness. Thus, for some of the women, their attachment to family and friends, continuity with social roles and familiarity with their environment allowed them to carve out a tolerable existence involving 'Getting on the best you can'.

4.1.5. Previous qualitative research in coping with dementia

The results of this study concur with previous qualitative research on coping with dementia (Clare, 2002a, in press; Gillies, 2000; Harris & Sterin, 1999; Keady & Nolan, 1995; Pearce *et al.*, 2002) that found that most of the participants were unaware of, or had forgotten their diagnosis. Whereas Gillies reported that participants conceptualised memory difficulties in terms of normal ageing,

participants in this study also gave various other explanations including social isolation, bereavement, stress, previous head injury and Alzheimer's disease.

Gillies interpreted minimisation and normalisation as strategies that allow the person to ignore the degenerative reality of the dementing process. In this study the women's use of normalisation is interpreted as an acceptance strategy, which made sense in the absence of accurate information. Minimisation in this study appears to be a protective strategy whereby the women attempted to cover up their embarrassment and humiliation. The carers in this study also reported the use of humour to deflect humiliation, which concurs with several previous studies (Harris & Sterin, 1999; Keady & Nolan, 1995; Pearce *et al.*, 2002). Other findings in this study that coincide with previous qualitative research on coping with dementia include: reliance on carers for support and as a proxy memory, maintaining a routine, making lists, the use of positive coping statement and attempts to maintain continuity by engaging in valued social roles and activities.

4.1.6. Gender differences

In considering how appraisal and coping processes might differ between men and women with early-stage Alzheimer's disease, some comparisons can be made between this study and that of Pearce *et al.* (2002). Appraisal and coping in men with early-stage Alzheimer's disease are described as involving a cyclical process of maintaining and reconstructing a sense of self. A model is proposed whereby men attempted to maintain their abilities, roles and sense of self, but if they became aware of their limitations they reappraised their situation and reconstructed their sense of self by adapting their expectations and roles.

Clare (2002a, in press) examined the coping strategies of nine men and three women with early-stage Alzheimer's disease. For this mixed sample, coping styles

and reactions to developing dementia are conceptualised as located on a continuum of self-maintaining to self-adjusting responding. It may be argued that the coping responses of women in the present study are located more at the self-maintaining side of this continuum. This therefore highlights possible gender difference in coping, where in contrast to men, the women's sense of self is not so much reconstructed, but dependent on an interpersonal context.

It is worth considering some differences between the men interviewed by Pearce *et al.* (2002) and the women in this study, as illustrated in Table 5. Given the small sample sizes, comparisons are best made in terms of descriptive statistics; further statistical analysis is unlikely to add meaningful information.

Table 5 Comparisons between women with early-stage Alzheimer's disease in this study and men in Pearce *et al.* (2002) in age and scores on the Mini-Mental State Examination, the Bristol Activities of Daily Living Scale and the Hospital Anxiety and Depression Scale.

	Women n=9			Men n=20		
	Mean	Std. dev.	Range	Mean	Std. dev	Range
AGE	77.89	5.18	70-86	74.80	5.67	63-84
MMSE	23.11	2.62	20-29	24.15	3.00	18-29
BADLS	18.78	5.93	10-25.5	10.9	6.73	0-23
HADS Anxiety	5.10	5.70	0-16	4.1	2.71	0-9
HADS Depression	4.61	4.18	0-13	2.45	2.13	0-8

The maximum possible score for the MMSE is 30; scores between 18 and 24 are classified as mild impairment and scores above 24 as minimal impairment (Hodges, 1994). The total possible score for the BADLS ranges from 0 (total independence) to 60 (total dependence). The total possible score for the two HADS subscales ranges from 0 to 21; scores below 8 points may be considered as non-cases, 8-10 as mild cases, 11-14 as moderate cases and scores of 15+ as severe cases (Snaith & Zigmond, 1994).

As might be expected from demographic trends, the women in this study appear to be slightly older than the men. Younger men may be less likely to attribute memory loss to normal ageing and older women may be experiencing more age related disability. There appears to be very little difference between the men and the women in their level of cognitive impairment as measured by the MMSE. However, the women appear to be less independent in daily living tasks as measured by the BADLS. Again this may be an age-related effect. It should be noted that the men's BADLS scores were obtained from their wives, whereas the women's scores were obtained from a variety of family members. This highlights the major difference between the samples in that most of the women were widowed. This could possibly account for the women appearing to be somewhat more distressed than the men. It is interesting that the women who met case definition for anxiety and depression on the HADS expressed concerns about connectedness. One reported stress due to domestic conflict, another worried about how long she and her partner would be able to live together, whilst another woman described her loneliness.

The higher-order theme of Connectedness in this study describes the women's attempts to maintain their sense of self and locates this in an interpersonal context of attachment and affiliation. Whereas reliance on wives was a significant theme in Pearce *et al.* (2002), what is different in this study is a reliance on a wider family network as well as friends and neighbours. This difference may be an effect of widowhood. However, this finding also concurs with previous research which reports that older women are more involved with and orientated to friendships than older men (Field, 1999).

In this study there appears to be an absence of any sense that the women were actively reconstructing their identity. This suggests that the coping styles of men and women are different. However, it is also possible that this finding could be due to

differences in interpretation whereby I was perhaps less attuned to the women's attempts to reconstruct their sense of self. It should also be noted that the themes describing reappraisal and reconstruction of the self in Pearce *et al.* (2002) were less frequent than themes relating to maintaining a sense of self. Given that Pearce interviewed twenty men, compared with nine women in this study, this may simply be an effect that was missed.

The suggestion that compared to men the women did not appear to be actively reconstructing or re-evaluating their sense of self may be due to differences in valued aspects of self-identity. Traditional gender roles emphasise male autonomy, whereas women's self-identity has been described as based more on their ability to develop and maintain relationships (Miller, 1976). Thus men in the early stages of dementia may experience a sense of lost autonomy and may draw on a repertoire of learnt coping responses such as problem solving strategies to maintain autonomy or redefine a sense of self by way of lowering their expectations. Self characteristics such as competence and self-reliance may be less easy to maintain than interpersonal skills such as warmth and humour (Coleman, 1999). For women with a repertoire of good interpersonal skills, maintaining a sense of self based on attachment and affiliation to others may be relatively less challenging. However, cognitive impairment and frailty make maintaining a sense of self dependent on the help of others. This is best illustrated in the results by Caroline who acknowledged a deep sense of loneliness and the need of having to make her own life, but lacked the resources and was therefore reduced to waiting to see who might come round.

Presenting such a stereotyped account of gender roles and people's sense of self feels rather uncomfortable. Although it is fair to say that older people's identities may be influenced more by 'traditional values', it should also be recognised that they have to a great extent been part of the enormous social changes that have occurred

in the last century. No claim can be made that striving for connectedness is a goal common to all older women. Referring back to Clare (2002a, in press), coping styles may be conceptualised as located on a continuum of responses. Women may therefore tend more towards the self-maintaining, and men more to the self-adjusting ends of the continuum. Conceptualising coping in this way allows for some overlap in the way that men and women cope with the onset of dementia.

Gender is but one of a multitude of factors that affect coping style. However, rather than assuming that a single model can describe coping in early-stages dementia, this study highlights that there may be distinct gender issues. The women in this study appeared to have values that located their sense of self in an interpersonal context. This finding resonates with feminist research on the interpersonal context of women's sense of self (Gilligan, 1982; Miller, 1976).

4.2. CRITICAL REFLECTION

In planning and conducting this research I have tried to adhere to established guidelines for qualitative research (Elliott, Fischer & Rennie, 1999; Yardley, 2000; Willig, 2001) to ensure that the process was methodologically rigorous. A consideration of this study in terms of seven guidelines for evaluating qualitative research (Elliott *et al.*, 1999) follows:

1. *Owning my own perspective*: My perspective is outlined in Chapter 2 and in the discussion that follows on personal reflexivity. Rather than guiding the investigation, the aim here is to reduce or at least acknowledge the influence of my theoretical and personal perspective.
2. *Situating the sample*: A description of the participants in terms of age, marital status, education, employment and their relationship with the family members who acted as informants, as well as information about their cognitive and functional impairment and self-reported mood state, is given in

Chapter 2. Some details have been changed to protect the women's confidentiality.

3. *Grounding the research in examples:* Illustrating the thematic account in the results with quotes from the transcripts allows the reader to evaluate the fit between the data and my interpretation, opening up an opportunity to conceptualise possible alternative meanings and understandings.
4. *Providing credibility checks:* Both the academic and field supervisors read the transcripts and audited the process of systematic analysis. A strength of this study lies in the triangulation of perspectives from the women and their carers in the analysis. The thematic account focussed on the women's perspective and used examples from the carers' interviews to provide confirmation or illustrate contradicting accounts. The study could have been improved by inviting the participants to comment on the summary themes, thereby providing testimonial credibility. This was not attempted because of time constraints and the ethical dilemma of asking participants to comment on material that they might find upsetting. A further option could be that of inviting comments from interested parties such as other professionals in the field or the Alzheimer's Society.
5. *Coherence:* The aim was to integrate the individual accounts into a coherent structure without losing sight of the women as persons in the data. It is recognised that structuring the eleven themes into three higher-order themes relied on my personal interpretation of the data. The model is thus described tentatively with a view of encouraging debate about clinical application and further research.
6. *Accomplishing the research task:* The research task was to explore the women's appraisal of their difficulties and their coping responses. The extent to which the participants are representative of women with early-stage Alzheimer's disease is discussed below as a limitation of the study.

7. *Resonating with the readers:* My aim in presenting the data has been to achieve a balance between allowing the reader to engage with the women as characters, whilst at the same time providing an analysis that may be of some practical use to those readers that work in the field.

4.2.1. Personal reflexivity

The themes derived from transcripts are a reflection of both my interpretations and the perspectives of the participants. Reflexivity ensures that the research process is scrutinised by identifying the ways in which my values, experiences and social identity have shaped the research process and findings. As discussed in Chapter 2, the values I bring to the research process are linked to my social identity as a gay man and previous experience in social work, counselling and health advice in the HIV field. I am aware that this has influenced my ethical stance about the women's rights to be informed of their diagnosis and to be involved in their treatment.

Although the findings resonate with feminist theory about the interpersonal basis of self-identity in women and previous research on attachment theory in dementia, the higher-order theme of Connectedness was not anticipated. The concept of self-identity based on a connectedness with family runs counter to my personal perspective, as I view my own identity as driven by autonomy. The research has contributed to changing and developing my clinical approach, which is mainly influenced by cognitive-behavioural theory. I am beginning to consider the importance of attachment in my clinical practice, drawing more on interpersonal and systemic approaches to therapy.

Minimisation, normalisation, acceptance and avoidance are coping strategies that could all have been anticipated from stress-coping theories and previous qualitative

research in coping with dementia. The possible influence of this in shaping my interpretation of the results needs to be acknowledged.

With hindsight some of my questions reflected my values in a way that I had not fully anticipated. For example, I was interested in identifying the women's early ambitions with a view to gaining some insight as to how this might have influenced their appraisal of their current situation. This approach reflected my own values and achievement orientation, and was also influenced by Maes *et al.* (1996) in their discussion of the need to consider the impact of a person's wider life goals on their appraisal of chronic illness. None of the women were able to remember what their ambitions might have been when they were young women. This was not just a product of cognitive impairment, as Anne's husband clarified when he pointed out that they were not brought up to have ambitions.

When asked whether there was anything she was proud of, Anne's response of 'swimming' surprised me, as she was not a professional swimmer. I expected her to be proud of her social roles as a wife, mother and grandmother. This illustrates some of my own values that people choose and should be proud of their social roles. There was a sense in some of the of women's accounts that for them their social roles were normal and given facts rather than choices. Perhaps for Anne swimming represented something she actually chose to do for herself.

My own personal reaction to some of the women's accounts was one of concern and sadness. I found myself responding to Caroline's account of loneliness with an attempt to provide some reassurance and encouragement, which led her to say that she was not miserable, probably because that was what she thought I wanted to hear.

As a researcher it was not appropriate to involve myself directly with the women's problems. These were either reported back to the referring clinician with the participant's permission, or carers were advised to raise issues of concern at the next clinic appointment. As a Trainee Clinical Psychologist with a background in counselling and social work I am used to having a more hands-on approach in these matters and it does leave me wondering how some of the identified problems were followed up.

4.2.2. Limitations of the study

Reflecting on the limitations of the study, five areas are identified for discussion: the appropriateness of the Mini-Mental State Examination to determine mild cognitive impairment; the extent to which the sample may be seen as representative of women's with early-stage Alzheimer's disease; the way the study was presented to the women; the influence of the structure of the interview schedules in eliciting certain responses; and possible motivations for the way the women presented themselves.

The use of the Mini-Mental State Examination in the inclusion criteria.

A Mini-Mental State Examination (MMSE: Folstein *et al.*, 1975) score of eighteen or above determined the criterion of early-stage cognitive impairment. Although some studies have shown it to be a valid and reliable screening measure to detect cognitive impairment in older people (Braekus, Laake & Engedal, 1992), it does have a number of limitations. It has been criticised for combining items that assess different areas of cognitive functioning (e.g. memory, concentration, praxis) into a single score. Identical scores may therefore obscure wide variation in cognitive profile.

The MMSE is both educationally and culturally loaded. Those with a below average education may score poorly, despite being unimpaired. Those with a high level of education may maintain high scores despite actual cognitive decline. This is a common difficulty of brief screening measures, but the MMSE is particularly susceptible to this effect (Christensen & Jorm, 1992; Orrell *et al.*, 1992; Tombaugh & McIntyre, 1992). In this study the lowest MMSE score was obtained from Brenda who was not born in the UK and had received the least number of years of formal education. Emma, with a first class university degree, provided the highest score in this study.

Of interest is that Emma's partner rated her as the least independent on the Bristol Activities of Daily Living Scale (BADLS: Bucks *et al.*, 1996), although she had the highest MMSE score. Harborne, Walker and Clare (2003) report poor correlations between cognitive and functional measures. This concurs with the dialectical model of Alzheimer's disease (Kitwood, 1997) where functional impairment is interpreted in terms of the interaction between neurological, psychosocial and environmental factors.

A practice effect may also inflate a person's MMSE score. It is commonly used as an efficacy measure for acetylcholinesterase-inhibitor medication in Alzheimer's disease. Apart from Brenda and Emma, all the rest of the women were receiving this treatment and would regularly be given the MMSE. Their scores may therefore give an inflated picture of their actual cognitive abilities.

Nevertheless, the advantage of using the MMSE in this study is that it allows for some comparison to be made with a previous study of men with early-stage Alzheimer's disease. As can be seen from Table 5, the men and women in the two studies had a very similar profile in terms of their MMSE scores.

The representativeness of the sample

The extent to which the participants were representative of women with early-stage Alzheimer's disease is perhaps less of an issue, as qualitative research does not necessarily aim at generalisability. The tentative relationships between the elements of the Level of Connectedness Model may be investigated further using quantitative research designs as discussed below.

Nevertheless it is worth speculating on certain idiosyncrasies in the sample. The women were recruited from specialist services for people with memory problems. It is likely that an expectation of memory decline in ageing will mean that a large number of people with early-stage Alzheimer's disease will not be in contact with services. The women were asked how they came to be referred to their local service. Although most of the women could not remember, carers indicated that referrals were often initiated by GPs as the women presented with other health complaints. One daughter specifically mentioned that she had asked her mother's GP for a referral to the memory clinic because she had read about drug treatments.

A particular concern as regards the representativeness of the sample is the large number of potential participants who declined to take part in the study (70%). This is exceptionally high and a common reason given was they had already taken part in other research. The carers acted as gatekeepers. Invariably it was the carer who responded to my telephone call and decided whether or not to arrange an informal meeting. One daughter commented that her mother had become distressed in a previous research study. Other husbands and daughters feared that the experience would be unsettling. Significantly, several carers declined to take part because they or the women were not 'coping'. In other words, it is likely that the women who had the most difficulties coping were the least likely to take part in research.

This study did not seek to recruit a homogeneous sample as regards ethnic or social-economic variables. The social diversity of the women added to the richness of the data and contributed to the study's ecological validity, because the majority of the women lived in multi-cultural inner-city neighbourhoods. It should be recognised that cultural factors will have an influence on illness representations and coping styles. In this study seven of the women were British, one Irish and one Southern European. Cultural differences may account for the Southern European woman identifying the absence of her extended family as a particular loss and the Irish Catholic woman's emphasis of the importance of her religion.

The presentation of the study as 'coping with memory problems'.

The study was introduced to the women as an investigation of 'How do older women cope with memory problems?' The reason for not using the term Alzheimer's disease was that it was rightly anticipated that not all the women had been informed of their diagnosis. It was also thought that it was possible that some women might disagree with the diagnosis. The aim was to use the women's own definition of their difficulties. The difficulty is that framing the research question in terms of memory problems may have encouraged the women to appraise their difficulties as normal.

My own stance that the women had a right to be informed of their diagnosis conflicts with this approach. I believe it colluded with the stigmatisation of the diagnosis and may have contributed to the avoidance themes. However, as a researcher it would also have been ethically wrong for me to inform the participants of their diagnosis. During initial telephone contacts with carers, some specifically voiced concerns and needed to be reassured that the label Alzheimer's disease would not be imposed. By contrast, one CPN declined to refer any participants because she felt the approach ethically wrong. Even with assurances that the term Alzheimer's disease

would be used if the women themselves referred to their difficulties as such, she felt that introducing the study as an investigation of memory problems stigmatised the diagnosis. My personal preference would have been to only recruit women who were open about their diagnosis, but this would have severely hampered an already difficult recruitment process. It would also have produced a different 'unrepresentative' sample. The strength of the approach that was used is that it accessed a group that reflects the more usual situation as currently found.

The influence of the structure of the interview schedules

The interviews commenced with questions about the women's past before going on to explore their appraisal of their memory problems and how they coped with their difficulties. Obtaining a biographical account was an important part of the study and it also served to create rapport. However, this structure had some unanticipated effects. Most of the women had some difficulties in answering questions about their past and this could have caused them some embarrassment, influencing some of the themes relating to protective strategies.

Time constraints meant that questions about the women's past made quite rapid leaps from childhood to adulthood. This had some curious effects, as some women seemed to have difficulty in switching between time frames. In Emma's account I thought it was odd, for someone who was one of the first women graduates from a prestigious university, that she chose winning the hundred yards race at school when eleven years old as one of the things she was most proud of. I think this was a product of the previous questions that had orientated her to her childhood. By contrast her partner thought that Emma was most proud of her work as a successful publisher. The same effect may explain Anne's 'swimming' response as discussed earlier.

When asked about a difficult moment in her life Hannah talked about being turned down for a job with the Air Ministry because of her political opinions. I assume she chose to talk about this because the interview had orientated her to that time. By contrast the husband thought his extra-marital affair would have been the most difficult moment in her life. It is unlikely that Hannah would have wanted to discuss this with me.

The women's presentation of self

The extent to which the women felt able to openly express their views about their difficulties is likely to have been influenced by the public self they wanted to display. The results show several examples of contradictions between the women presenting themselves as 'alright' and their carers accounts of them covering up their difficulties due to embarrassment and humiliation. Although the carers' accounts make intuitive sense it should also be recognised that they do not hold a monopoly on the truth.

An important issue here is that the public self that the women displayed in the interviews was inexorably tied up with their perception of whom it was they were talking to. At times it appeared as if the women were uncertain about who I was or what I represented. During Anne's interview she seemed uncertain as to whether I worked at the memory clinic. This may have made her cautious about talking about her memory difficulties. An example was her tone of voice when she said her memory was fine, which was very insistent.

Irene said she did not worry about anything and perhaps the clue here is in her words "I'm quite happy with things as they are". Her daughter described how Irene was worried that I might be coming around to put her in a home. Although she told Irene not to be "silly", perhaps the irony is that this was precisely my role as a social worker in the past, where I would visit elderly people to make a P3 residential

accommodation application. Thus from my perspective Irene's concerns were far from "silly".

Brenda wished someone would help her with the verbal abuse she received from her son-in-law. As I left the house she thanked me and gave me a hug, which left me wondering who she thought I was and what she hoped I might do for her. Perhaps I did play the role she expected of me by informing the local psychology service about the situation.

Some of the women may have experienced the interview as an assessment of their memory. Gill, for example, gave the impression that she expected me to test her memory. I spent some time assuring her that this was not my intention. Nevertheless she still wondered whether some of my questions were intended to catch her out and this indicated that she felt the need to be on her guard.

Some of my questions caused the women some difficulty. Deirdre for example became apologetic about not being able to answer some questions and went on to tell me that she did remember other things. Given Deirdre's daughter's agenda of moving her mother into a home, Deirdre's interjections during her daughter's interview were mostly aimed at letting me know that she was capable of managing at home, which again points to her experiencing the interview as an assessment.

The interview process could have been improved by more general questions that externalise the context of memory problems. Killick and Allan (2001) describe the use of a photograph of an older person, which the interviewer identifies as a person with memory problems. The participant is then asked to consider what kind of difficulties this person might experience. The assumption is that the person's responses will be based on her own experience of memory problems. By

externalising the issue the person may not necessarily experience a sense of personal embarrassment, which may free her up to give a more open account of the impact of memory problems.

4.3. FUTURE RESEARCH

The Level of Connectedness model proposes a number of hypothesised relationships and causal explanations such a relationship between the women's level of connectedness and well-being, connectedness facilitating acceptance and threats to connectedness promoting protective strategies. Future research could aim to operationalise these concepts and investigated their relationship in quantitative research.

My interpretation that the women strived for connectedness, and previous research indicating that men strive for autonomy, may well be based on internalised models of how men and women operate. Striving for autonomy and connectedness may well represent a tension or dilemma for both men and women, which would fit with theories of attachment that describe how secure attachment allows a person to explore his or her environment. Future research may involve the development of assessment tools of connectedness, autonomy and well-being to explore the relationships between these concepts in people with dementia.

In this study several carers described differences in the women's appraisal and coping as they looked back over time. Thus, although Caroline was acutely aware of her memory problems and attributed this to her loneliness, her granddaughter described how in the past Caroline would deny she had any memory difficulties and would become agitated if the problem was pointed out. It appeared that a prolonged hospital admission had contributed to a loss of skills, which had made it difficult for Caroline now to deny that she had memory problems.

Hannah mentioned being distressed by her memory loss, but also asserted that she had accepted it, which may reflect a process of coming to terms with her limitations. This was also reflected in her husband's account of her becoming "more tolerable". An understanding of what brings about such changes requires a longitudinal study of appraisal and coping processes.

The experience of dementia as a threat to connectedness should be examined in the context of the progressive degenerative nature of Alzheimer's disease. The threat to connectedness will therefore be experienced at different levels according to the stage of cognitive impairment ranging from initial uncertainty about forgetfulness, disorientation and confusion, to higher levels of insecurity as described in the work of Miesen (1992, 1993) as the phenomenon of parent-fixation. Models of coping also suggest that as people's appraisal of their illness change so will their coping responses and the impact of dementia will also affect coping resources over time. Future research will need to explore changes in coping over time as people are confronted with further challenges and cognitive decline.

4.4. IMPLICATIONS FOR CLINICAL PRACTICE

Previous research (Clare, 2002a; Pearce *et al.*, 2002) suggests that people with dementia actively engage in a continual process of appraising and coping with their difficulties. This study points to this appraisal being made within a context of personal and cultural values, in this case connectedness. It contributes to understanding the appraisal and coping processes in Alzheimer's disease in an interpersonal context. With the proviso that the Level of Connectedness Model requires further investigation, it may provide a useful focus for psychosocial interventions. The suggestion is that psychological and social services have a vital role to play in helping people with dementia create positive identities. It supports a

person-centred care focus on the person's history and values and proposes that interventions should involve the person's wider network of family and friends.

4.4.1. Good practice

Before considering such interventions I return to my own stance that an ethical, effective and respectful approach requires efforts to keep the person fully informed. It was difficult to establish from the referring clinicians exactly what the women had been told about their diagnosis prior to the interviews. Five carers reported that they had not been informed of the woman's diagnosis by the clinic; some had guessed or found out by other means. This appears to be indicative of a culture where there is little open communication between the women, their relatives and professionals.

This echoes findings of previous studies (Clare, in press; Clarke and Keady, 1996; Husband, 1999). For example, Clarke and Keady (1996) also reported that some of their participants and their carers did not know about the diagnosis, which tended to be referred to as 'memory problems'. It is likely that older people with dementia will be more inclined to accept memory problems as part of normal ageing, which may account for the finding by Husband (1999) that doctors were more likely to inform younger people of their Alzheimer's disease diagnosis. Similar to this study, Husband (1999) also found that only a minority of carers were given an opportunity to discuss the issues involved with a professional and younger carers were more likely to feel that such an opportunity would have been useful. In their autobiographical accounts, Davis (1989) and McGowin (1993) also felt they lacked information and support. They expressed their concern about the length of time it took to establish a diagnosis and being kept in the dark about the outcome of assessments.

It may be useful here to review how some of these issues related to the women in this study. In reviewing Emma's medical file I noted that a diagnosis of probable Alzheimer's disease had been made. However, there was no record in the file of Emma having been informed of her diagnosis. Upon interviewing Emma and her partner Harry, they expressed their concern and anger that they were still waiting to hear what the diagnosis was seven months after the assessment. In the absence of a diagnosis they were both left to find their own explanation for Emma's difficulties. She was aware she had memory problems, but could not account for this other than in terms of old age. After the interview Harry commented that he wondered whether Emma had "that condition that the famous woman author had; the one they made the film about". He was particularly concerned because he thought she had deteriorated further since the assessment, highlighting how such delays effectively deny a person treatment. It is of some concern that this experience may not be uncommon, as Brenda and her daughter told an almost identical story.

Fiona did not appear to have been told that she had Alzheimer's disease either. In the absence of a diagnosis she looked for an explanation for her memory problems in terms of a fall on the ice in her 50s. Fiona looked to medication to alleviate her condition, which came out as a main theme in her account and was confirmed by her daughter. Aricept seemed to have had a positive effect. For me personally, treating somebody without sharing a diagnosis raises real ethical issues about informed consent. However, her daughter thought her mother would worry more and get depressed if she knew she had Alzheimer's disease. The daughter had never been told about the diagnosis either, but saw it written in her mother's notes on the GP's computer screen. She did not necessarily disagree with the diagnosis being withheld from her mother, but thought that she as carer should have been told. Again this raises ethical issues about whether a carer may be informed of a

diagnosis without the patient's consent, as well as issues about allowing someone to find out a diagnosis without giving them support and information.

Gill's daughter suspected her mother had Alzheimer's disease, but was unsure, as the doctor had not talked about it. In the absence of professional support and information the daughter relied on media reports about the benefits of chewing gum and drinking coffee in the hope that this might help. She tried to get her mother to do crosswords to stimulate her mind, although she knew her mother disliked doing them.

What these accounts show is that there are gaps in good practice in terms of keeping people informed about the assessment procedure and the provision of accurate information about the diagnosis, treatment and available support. Reflecting on my experience as a health adviser and counsellor in sexual health, I would argue that there are real advantages in providing pre-assessment counselling or discussions to provide accurate information about dementia and the available treatment and support, and to provide an overview of what the assessment will involve, possible outcomes and how a diagnosis will be given. This will allow people to make an informed decision as to whether they wish to have a neuropsychological assessment, whether they wish to know the diagnosis and with whom they would like this information to be shared. My own experience has shown the importance of backing up good practice with keeping accurate records of decisions, providing clear written information and offering post-diagnosis counselling. Husband (2000) supports the view that it is important to provide counselling at the time of receiving a diagnosis of dementia.

The difference with the HIV model of informed consent is the question of the extent to which people with cognitive impairment are able to take part in the process.

Gaining informed consent is a process that requires the person to be fully informed, consent being given freely and willingly, and that the person is competent. People with early-stage dementia will generally be able to understand and give consent if the procedures are flexible and allow adequate time for the repetition of information. A lack of competence cannot be assumed just because a person has dementia. It is the responsibility of the clinician to assess competence and determine whether it is in the person's best interest for carers to be involved. There appears to be a growing consensus that people with early-stage dementia have the right to be informed of about their diagnosis even if this goes against the wishes of the family (Maguire *et al.*, 1996; Rice & Warner, 1994)

4.4.2. Counselling and support

In this study Caroline's granddaughter described her as happier when she was in contact with others and this helped her to remember more. The granddaughter believed that Caroline would benefit from a visitor. In fact Caroline did appear to enjoy my visit and through a process of questioning she was able to gradually remember her children's names and gain a sense of achievement from this. The presentations of several women during the interviews appeared to suggest that they might benefit from counselling to help them reconstruct some of their memories.

Cheston (1996) described the importance of storytelling in a psychotherapy group for people with dementia in helping people make sense of their current experiences by making links with the past. Aspects of people's life-stories and their present day experiences may be metaphorically similar. This allows them to explore and express some of their experiences of dementia. Listening to the content of the stories that people with dementia tell will help give some indication of their present day concerns. This was apparent in this study; for example Caroline talked about being lonely in her childhood, Gill talked about times when she was afraid of being alone

and Brenda talked about having been loved in the past. These stories appear to give some indication of the women's present day concerns about their connectedness.

This study highlights the need for interventions to uncover preferred identities by understanding the person's values in the context of her biographical account. Coleman (1999) claims that there is evidence that many old people in our society lack the encouragement they need and the audience to whom they can tell their story. Storytelling, or reminiscence work may help the person to re-establish an identity other than that of a person with dementia. The telling of life-stories is also an important part of person-centred care, allowing the carer to engage with the person rather than the dementia (Kitwood, 1997). According to Mills and Coleman (1994), much can be done to preserve a more coherent sense of self by sensitive counselling and repeated encouragement of individuals to recall their story.

As dementia progresses there comes a point where others must sustain a person's story and this is more likely to occur if efforts have already been made to encourage the person to keep active her own account of her life-story. Various kinds of individual and group reminiscence therapy interventions have been developed, often using aids such as music and photographs (Mills & Coleman, 1994; Woods, Portnoy, Head & Jones, 1992). Shenk *et al.* (2002) examined the usefulness of life-story development in maintaining self-identity and personhood in dementia. Life-story work in cognitive impairment may require a carer to facilitate the co-construction of memories. Shenk *et al.* (2002) showed that over time it is possible to help even someone with a relatively high level of cognitive impairment to reconstruct memories that enhanced a sense of self. Romero and Wenz (2001) incorporate life-story work into a multi-component intervention (described below), which included the use of computers and video to record valued aspects of self-identity.

Psychotherapy for people with dementia has been a relatively new development (Duffy, 2002). Traditional therapists have considered persons with dementia as non-amenable for psychotherapeutic change as their interventions depend on a high level of verbal communication. According to Duffy (2002), persons with dementia can engage in psychotherapeutic processes, but this requires an approach that focuses less on the domains of language and logic. The 'therapeutic posture' is described as the essential ingredient in providing psychotherapy to older people with dementia, which includes a willingness to slow down the pace, staying with the moment, accepting not being recognised by the client and the use of touch in establishing psychological connectedness. The role of intimacy in therapy takes on a particular significance in working with older women. Depression in women with dementia is discussed in relation to disrupted relationships and the interpersonal aspect of women's sense of self (Duffy, 2002). The importance of intimacy in working with older women with dementia is described as a way of counteracting this experience of loss.

Whereas individual and group counselling may facilitate a coherent sense of self, support groups may help undermine the stigma of a diagnosis. Support groups have played an important role in providing education and assistance to the carer for people with dementia. However, more recently support groups have been developed aimed at people with dementia, or for both people with dementia and their carers. Such groups aim to help people find a balance between optimism and realism by providing a combination of education, emotional support and assistance (Yale, 1995).

In this study the one woman who openly referred to Alzheimer's disease in the interview attended a support group piloted by the day hospital. The daughter explained that she felt that this had helped her mother to talk openly about

Alzheimer's disease. However, she also acknowledged that her mother was good at covering up because she would not want other people to know. She believed that her mother made a distinction between professionals with whom she felt able to openly discuss her diagnosis, and others from whom she sought to hide her difficulties. Perhaps the benefit of such support groups is that of allowing people to engage in their treatment.

Reviewing the clinical literature on individual and group interventions, Cheston (1998) noted that there has been little research into the effectiveness of this work. It is argued that clinical research should adopt case study or single-case designs for evaluating new clinical developments. Scott and Clare (2003) reviewed a range of group interventions including reality orientation, validation, reminiscence, cognitive stimulation, memory training, psychodynamic and cognitive-behavioural psychotherapeutic approaches, and support groups. Again a lack of rigorous evaluation of the interventions was noted and qualitative and multiple single-case approaches are recommended. The authors also point to the importance of providing people with dementia with choice in whether to attend interventions aimed at emotional expression or enhancing cognitive functioning, at an individual or group level. Professionals should also aim to enable people with dementia and their carers to determine what outcomes of such interventions are relevant and acceptable.

4.4.3. Including the carer

The study points to the importance of including the carer in psychosocial interventions for two reasons: firstly, the women's need for connectedness and secondly, evidence of carer strain in the carers' accounts. Carer strain and concerns about connectedness may develop into a cycle of malignant social psychology, of which there is some evidence in this study. For example, Deirdre's daughter told of the stress of providing for her elderly mother with Alzheimer's disease, her learning

disabled brother and her sister who had enduring mental health problems. Care for her mother and brother was provided at a distance as she lived some miles away with her husband and children. She also held down a job as a secretary. In juggling these various tasks she came into conflict with her mother in wanting to move her into a nursing home, a move that was resisted by her mother who worried about leaving her learning disabled son.

Emma's partner Harry was distressed by her difficulties. He clearly admired her previous intellectual abilities and found it difficult to reconcile himself with how she is now. In particular he experienced her aggression towards him as hurtful. Harry admitted that he had hit her, as he could find no other way to stop her screaming.

Fiona's daughter was also clearly under some strain. She worried about how Alzheimer's disease was going to progress and the burden of coping with her mother on her own, although she had more recently enlisted the support of one of her brothers. She was at a loss as how to deal with her mother's personal hygiene. She wished she could do more for her mother, but felt unable to do so because of her work commitments. This made her sensitive about other people's comments, which she experienced as critical although she recognised them as well-intentioned.

According to Romero and Wenz (2001), therapeutic interventions with people with dementia should aim to stabilise and preserve two systems: the self as an intrapsychic system, and the social network as an interpersonal support system. Maintaining the person's sense of self is important for well-being and allows her to make better use of her cognitive abilities and reduces disturbed behaviour. In planning interventions for self-maintenance it is important to take the into account the person's goals and values, especially with regard to the present situation and experience of dementia. People with dementia depend on social support to manage their daily lives. Maintaining the support system requires adequate provision of

support for carers. Providing counselling and support improves carer well-being and makes it more likely that carers will feel able to care for the person at home.

Based on this premise, Romero and Wenz (2001) developed Self-Maintenance Therapy (SMT), a treatment programme for people with dementia and their caregivers, which aimed to prepare them for life with a chronic progressive disease.

The intervention has four components:

1. Psychotherapeutic support, which aims to maintain a sense of meaningfulness, offering opportunities for personal growth and orientating the person to goals in life.
2. Self-knowledge training, which focuses on biographical accounts, using stories, family photos, tapes with music to stimulate and support the person's sense of continuity and identity. As the person tells her life-story over several sessions, the therapist identifies the relative importance of themes by looking at which stories elicit emotional reactions and are repeated most often.
3. Facilitation of satisfying everyday activities, by helping the person to resume valued activities, replacing previous activities that the person can no longer engage in, and integrating activities in the home or community in an everyday routine.
4. Validating communication in caregiving, by educating the carer to understand the person's way of making sense of her experience.

In evaluating the programme, Romero and Wenz (2001) reported a consistent improvement in depression and other psychopathological symptoms in the person with dementia and the caregiver. The authors stress the importance of this finding by pointing to the role of psychopathological symptoms as a major precipitating factor in carers' decisions to move the person with dementia into residential care. The intervention supported the premise that the behaviour and affect of the person

with dementia depend to a large extent on the competence of the caregiver. This supports the coping literature on the inter-relationship between the coping in the person with dementia and the caregiver (Coyne & Fiske, 1992).

Systemic approaches to family therapy may provide a useful focus for connecting the women to their support networks, whilst bearing in mind the different needs of the individuals in the system. Looking at the inter-relationship of coping in the carer and person with dementia also fits well with the Adaptive Coping Model presented by Dröes *et al.* (1997, 2001), which attempts to integrate the adaptive tasks faced by the person with dementia with the support needs of the carer. Moniz-Cook and Woods (1997) also showed how involving the carer can be beneficial in psychosocial interventions, reporting increases in behavioural memory test scores in the person with dementia as well as improvements in carer well-being.

4.5. CONCLUSION: FACILITATING CONNECTEDNESS

This study contributes to understanding the appraisal and coping processes in women with early-stage Alzheimer's disease and builds on person-centred (Kitwood, 1997) and social constructionist approaches (Sabat & Harré, 1992; Sabat, 1994, 2001) by highlighting the role of others in helping women maintain a sense of self. By comparing the results with previous research on men coping with early-stage Alzheimer's disease, possible gender difference in coping are identified. Pearce *et al.* (2002) described the appraisal and coping process of men with early-stage Alzheimer's disease as a cyclical process of reappraising and reconstructing a sense of self. In this study the women's sense of self was not so much reconstructed but dependent on an interpersonal context. Coping styles and reactions to developing dementia may be conceptualised as located on a continuum of self-maintaining to self-adjusting responding (Clare, 2002a, in press). Women may therefore tend more towards the self-maintaining, and men more to the self-

adjusting ends of the continuum. Conceptualising coping in this way allows for some overlap in the way that men and women cope with the onset of dementia.

The women in this study experienced memory problems as a threat to connectedness or sense of self, derived from attachment to family and friends, affiliation with social roles, familiarity with surroundings and a sense of continuity with the past. Threats to the women's connectedness may have motivated them to use protective strategies to underplay their difficulties by way of minimisation and avoidance, thus conveying a sense that memory loss was not a problem. Acceptance was conveyed by the use of self-statements about managing, normalisation and problem solving, which may have been facilitated by higher levels of connectedness.

The Level of Connectedness Model presented in Figure 2 (p.117) may provide a useful focus for psychosocial interventions. The importance of attachment and affiliation with others, social roles and the environment fits well with the concept of personhood (Kitwood, 1997). In identifying the importance of the level of the women's connectedness for their well-being, the study demonstrates how social care practices can strengthen or weaken personhood. The suggestion is that psychological and social services have a vital role to play in helping people with dementia create positive identities. It supports a person-centred care focus on the person's history and values and proposes that interventions should involve the person's wider network of family and friends. A recognition of the importance of interpersonal aspects of coping may be an important factor for developing appropriate and sensitive interventions to maximise self-efficacy and combat threats to self-identity in women with early-stage Alzheimer's disease.

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**APPENDIX A
DOCUMENTATION OF ETHICAL APPROVAL**

North East London 

Health Authority

The Clock House East Street BARKING IG11 8EY

Tel: 0208 532 6221 (direct line) (If I am unavailable
please leave message)

Mr. M. van Dijkhuizen
Trainee Clinical Psychologist
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 8BT

18th April 2002

Dear Mr. Van Dijkhuizen

**Re: LREC (B&H) 2002/8
Appraisal and coping process of women with early stage Alzheimer's
disease**

I am pleased to advise you that the above-mentioned research application was considered by the Barking & Havering Local Research Ethics Committee on the 10th April 2002 and the Committee was able to approve the ethical aspects of the study without condition.

The Committee looks forward to receiving a final report of your research findings in due course.

Yours sincerely

**Mrs. J Irwin-Hunt
Chair LREC**

Camden & Islington Community Health Service LOCAL RESEARCH ETHICS COMMITTEE

Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
St Pancras Hospital, London NW1 OPE
tel: 020 7530 3376 fax: 020 7530 3235
e-mail: ayse.ali@cichs-tr.nthames.nhs.uk
Chair: *Stephanie Ellis* Administrator: *Ayse Ali*

3 April 2002

Mr Michael van Dijkhuizen
Sub Department of Clinical Psychology
University College London
Gower Street
WC1E 6BT

Dear Mr van Dijkhuizen

LREC Ref: 02/27 (please quote in all further correspondence)

Title: Appraisal and Coping Processes of Women with Early Stage Alzheimer's Disease

Thank you for submitting the above project for ethical review. The Committee gave careful consideration to your proposal at its meeting on 25 March 2002, and it was agreed that before a favourable opinion could be offered the following point needs to be addressed.

- Your application indicates that you intend to use semi-structured interviews although there was no copy of this submitted. The committee wondered what kinds of questions would be asked, how long it would take to complete as there were concerns that this might be too much to cope with given that this is a vulnerable group of people.

Please forward any requested additional material/amendments regarding your study to the Ethics Committee Administrator or the Chair at the above address.

PLEASE NOTE THAT THIS PROJECT SHOULD NOT PROCEED UNTIL THIS ETHICS COMMITTEE HAS CONFIRMED IT HAS NO ETHICAL OBJECTIONS TO THE STUDY AND THE NHS BODY/ORGANISATIONS HOSTING THE RESEARCH HAVE, IN WRITING, GIVEN THEIR APPROVAL TO COMMENCE THIS STUDY.

If you have any queries, please do not hesitate to contact the Local Research Ethics Administrator at the address above.

Yours sincerely -



Stephanie Ellis

Ethics Committee Chair

North East London



Health Authority
The Clock House East Street BARKING
IG11 8EY

Tel: 0208 532 6221 (direct line) (if I am
unavailable please leave message)

Mr. M. van Dijkhuizen
Trainee Clinical Psychologist
Sub Department of Clinical Health Psychology
University College London
Gower Street
London WC1 6BT

11th November 2002

Dear Mr. M van Dijkhuizen

Re: LREC (B&H) 2002/8
Appraisal and coping processes of women with early stage
Alzheimer's disease

Thank you for your letter of the 25th September 2002. I am pleased to advise you that the Barking & Havering Local Research Ethics Committee approved the amendment to the inclusion criteria on the 6th November 2002.

The Committee wishes you well with your research.

Yours sincerely

Mrs. J Irwin-hunt PP
Chair B&H LREC

Camden and Islington Community Health Service

LOCAL RESEARCH ETHICS COMMITTEE

Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
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2 May 2002

Mr Michael van Dijkhuizen
Sub Department of Clinical Psychology
University College London
Gower Street
WC1E 6BT

Dear Mr van Dijkhuizen

LREC Ref: 02/27 (please quote in all further correspondence)

Title: Appraisal and Coping Processes of Women with Early Alzheimer's Disease

Thank you for your letter dated 26 April 2002 addressing the concerns raised by the committee. I am pleased to inform you that after careful consideration the Local Research Ethics Committee has no ethical objections to your project proceeding. This opinion has also been communicated to the North Central London Community Research Consortium.

PLEASE NOTE THAT THIS OPINION ALONE DOES NOT ENTITLE YOU TO BEGIN RESEARCH.

Camden and Islington Community Health Service LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility to decide whether or not the project should go ahead, taking into account the ethical advice of the LREC¹. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management, who will need to be assured that the researcher holds an appropriate NHS contract, and that indemnity issues have been adequately addressed.

N.B. Camden and Islington Community Health Service LREC is an independent body providing advice to the North Central London Community Research Consortium. A favourable opinion from the LREC and approval from the Trust to commence research on Trust premises or patients are **NOT** one and the same. Trust approval is notified through the Research & Development Unit.

The following conditions apply to this project:

- ◆ You must write and inform the Committee of the start date of your project. The Committee (via the Local Research Ethics Committee Administrator or the Chair at the above address) must also receive notification:
 - a) when the study commences;
 - b) when the study is complete;
 - c) if it fails to start or is abandoned;
 - d) if the investigator/s change and
 - e) if any amendments to the study are made.
- ◆ The Committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the project.

¹ Governance Arrangements for NHS Research Ethics Committees, July 2001 (known as GAFREC)

- ♦ It is the responsibility of the investigators to ensure that all associated staff, including nursing staff, are informed of research projects and are told that they have the approval of the Ethics Committee and management approval from the body hosting the research.
- ♦ The Committee will require a copy of the report on completion of the project and may request details of the progress of the research project periodically (i.e. annually for longer projects).
- ♦ If data is to be stored on a computer in such a way as to make it possible to identify individuals, then the project must be registered under the Data Protection Act 1998. Please consult your department data protection officer for advice.
- ♦ Failure to adhere to these conditions set out above will result in the invalidation of this letter of no objection.

Please forward any additional information/amendments regarding your study to the Local Research Ethics Committee Administrator or the Chair at the above address.

Yours sincerely


Stephanie Ellis
Chair, LREC



Sub-Department of Clinical Health Psychology

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Stephanie Ellis
Chair LREC
Camden & Islington Community Health Services
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3rd Floor, West Wing,
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London
NW1 0PE.

8 October 2002

Dear Ms Ellis,

Re LREC Ref 02/27
Appraisal and coping processes of women with early stage Alzheimer's disease

I am writing to request ethical approval for an amendment to my research thesis. The Camden & Islington Community Health Service Local Research Ethics Committee approved the above research application in April 2002. Since then it has proved difficult to recruit participants meeting all of the referral criteria set out in the original application.

The criteria for inclusion are defined on page 7 of the application form as follows:

1. 10 Women diagnosed with probable dementia of Alzheimer type (DAT)
2. Mild cognitive impairment defined by Mini-Mental State Examination score of 18 or above
3. Living with a partner who is willing to participate
4. Fluency in English
5. Able to give informed consent
6. Exclusion of other chronic physical and mental illnesses

An examination of clinical records has revealed that point 3 is severely limiting the search for potential participants. It appears that in many cases the woman with Alzheimer's disease no longer lives with a partner, but often has access to a carer (usually

one of her children). The woman may be living with a carer, although in some cases the woman lives alone and a daughter or son living locally provides care.

The inclusion of a partner in the research was intended as an additional source of information. I believe that a carer who knows the woman well will provide equally valid information. I therefore propose to change point 3 to "*Access to a partner or carer who is willing to participate*". This change does not alter the research design, but broadens the scope for additional information. It will significantly increase my ability to access potential participants. Information sheets intended for the partner can easily be amended to take account of the carer's relationship to the woman.

I would be grateful if this amendment could be considered at the next Committee meeting.

Yours sincerely,

Mike van Dijkhuizen
Trainee Clinical Psychologist.

Camden & Islington Community Health Services LOCAL RESEARCH ETHICS COMMITTEE

Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
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Chair: *Stephanie Ellis* Administrator: *Ayse Ali*

23 October 2002

Mr Michael van Dijkhuizen
Sub Department of Clinical Psychology
University College London
Gower Street
WC1E 6BT

Dear Mr van Dijkhuizen

LREC Ref. 02/27

Title: Appraisal and coping processes of women with early stage Alzheimer's disease

Thank you for your letter dated 8th October 2002 outlining some proposed amendments to the above study.

I am please to inform you that the ethics committee has no objection to including carers instead of partners where appropriate providing that informed consent is sought in all cases. Please note that the conditions set out in our letter dated 2 May 2002 still apply.

Please forward any additional material to the Ethics Committee Administrator at the above adress.

Yours sincerely


Stephanie Ellis
Committee Chair

HARROW RESEARCH ETHICS COMMITTEE

(Chairman: Dr Gwen Sayers)

Room 5BB 013

Northwick Park Hospital

☎ 020 8869 2011

Fax: 020 8869 2014



THE NORTH WEST LONDON HOSPITALS
NHS TRUST
WATFORD ROAD HARROW
MIDDLESEX HA1 3UJ

8 January 2003

Mr M van Dijkhuizen
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 8BT

Dear Mr van Dijkhuizen

Ethics Submission No 3082: Appraisal and Coping Processes of Women with Early Stage Alzheimer's Disease

The above project was approved by the Harrow Research Ethics Committee at its meeting on 6 January 2003. *Please note that, before you can proceed with the study, you will need to obtain formal authorisation from the NHS institution where it is to be undertaken.*

As this was a MREC approved project, consideration was restricted mainly to the suitability of the local researcher; the suitability of the site; the suitability of the subjects; and local aspects of the patient information sheet and consent form.

Set out overleaf is the REC membership list which should, if applicable, be copied to the sponsoring organisation.

General Practitioners should be kept informed of research work affecting their patients, particularly when the patient's involvement continues after discharge from hospital.

All adverse events arising during the course of this study should be notified, but please note that the Committee is only concerned to receive such notifications as they relate to subjects participating in trials in Harrow. Investigators undertaking trials on behalf of drug companies are asked to refrain from sending other adverse event reports, unless there are very exceptional circumstances.

The Committee operates according to GCP in most important respects.

Yours sincerely

Ms Angela Barst
Acting Administrator

EC No: 02.164
R&D No: 02/X0236E
Registered Date: 9.12.02

St Mary's 

NHS Trust
Local Research Ethics Committee, R&D Office
Mailbox 121, St Mary's Hospital, Praed Street, London, W2 1NY
Tel No: 020 7886 6514: Fax No: 020 7886 1529
Email: Ros.Cooke@st-marys.nhs.uk

23 January 2003

Mike van Dijkhuizen
Trainee Clinical Psychologist
Sub-Department of Clinical Health Psychology
Uduniversity College London
Gower Street
London WC1E 6BT

Dear Mr van Dijkhuizen

Appraisal and coping processes of women with early-stage Alzheimer's disease

Mike van Dijkhuizen, Dr Clare, UCL Psychology
EC No 02.164 R&D No: 02/X0236E

On behalf of the members I am pleased to say that St Mary's Local Research Ethics Committee (LREC) discussed the above project at their meeting on 23 January 2003. The following grid shows the documents reviewed.

Research documents approved	Original date	Decision date
LREC application form	9.12.02	23.1.03
Consent form	9.12.02	23.1.03
Information sheets revised	14.1.03	23.1.03
HAD Scale	Undated	23.1.03
Protocol	undated	23.1.03

The members of the Committee present agreed there is no objection on ethical grounds to the proposed study, I am therefore happy to give you the favourable opinion of the committee in accordance with the ICH Good Clinical Practice Guidelines.

This decision is given on the understanding that the research team will observe strict confidentiality over the medical and personal records of the participants. It is suggested that this be achieved by avoidance of the subject's name or initials in the communication data. In the case of hospital patients, using the hospital record number can do this; in general practice, the National Insurance number or a code agreed with the relevant GP.

Vice Chairman's initials



APPENDIX B PARTICIPANT INFORMATION SHEETS

Information sheet for woman with Alzheimer's disease

Amend [] as appropriate.

(Local Mental Health Trust Headed Paper)

How do older women cope with memory problems? RESEARCH INFORMATION SHEET

Dear Mrs

I would like to invite you and your [daughter] to take part in a research study. [Local clinician] at the [local service] has referred you to me. Before you decide whether or not to take part, I would like to make sure that you understand why the research is being done and what it will involve.

What is the purpose of the study?

This research will look at how older people cope with memory problems. A better understanding of how older people experience memory problems is important. It will help doctors, psychiatrists and psychologists to think about how best to support people with memory problems.

Why have you been chosen?

You have been asked to participate in this study because you have attended [local service] for memory problems. For this study I will be talking to ten women and a family member. All these women will have attended a clinic for memory problems in the same way that you did.

Do you have to take part?

You do not have to take part in this study if you do not want to. If you decide to take part you and your [daughter] will be asked to sign a consent form. You may change your mind and withdraw at any time without having to give a reason. Your decision whether or not to take part will not affect the care you receive from the NHS in any way.

What will happen if you take part?

I would like to talk with you about your past experiences and your current memory problems. The interview will last about 45 minutes and will take place at your home at a time that is convenient to you and your [daughter]. The interview will be tape-recorded so that I can look back at our conversation and compare it with similar interviews that I have of other women with memory problems. At the end of the interview you will be asked to complete a short questionnaire. The questionnaire will ask you about how you are feeling and will take about 15 minutes to complete. I also wish to interview your [daughter] for about 30 minutes. I will ask her similar questions and she will also be asked to complete a short questionnaire.

What are the possible benefits or disadvantages to taking part?

These interviews are not part of your treatment. Some people find it helpful to talk in confidence about their experiences and difficulties. Other people may feel upset when they are asked about their life history and memory problems. I will try to be sensitive and not upset you. I hope that you will find the interview helpful and enjoyable. If you do feel upset by any of my questions I can offer you support from your local psychology service, but I will only contact them with your permission.

All proposals for research are reviewed by the ethics committee before they can proceed. The [Local Research Ethics Committee] reviewed this research proposal.

Will taking part in this study be kept confidential?

All information that is collected about you during this research will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it. I will erase the tape-recordings after I have studied them.

What will happen to the results of this study?

I am a Trainee Clinical Psychologist at University College London. The results of this study will be presented in my thesis and in a paper that will be presented to a psychological journal for publication. It will not be possible for anybody to identify you in the published results. This research will take me about one year to complete. I will send you a short summary of the findings when the research is completed.

What will happen next?

Within the next few days I will contact you and your [daughter] by telephone and arrange to make an appointment to meet with you. This will be an informal meeting during which you will have the opportunity to ask me questions about the study. If you then agree to take part in the study I will arrange another appointment to come and see you.

Thank you for your time in considering this study.

Mike van Dijkhuizen
Trainee Clinical Psychologist
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT
Tel 020-7490 5696 (answer machine)

Information sheet for carer

Amend [] as appropriate.

(Local Mental Health Trust Headed Paper)

How do older women cope with memory problems? RESEARCH INFORMATION SHEET

Dear

I would like to invite you and your [mother] to take part in a research study. [Local clinician] at [local service] has referred you and your [mother] to me. Before you decide whether or not to take part, I would like to make sure that you understand why the research is being done and what it will involve.

What is the purpose of the study?

This research will look at how older people cope with memory problems. A better understanding of how older people experience memory problems is important. It will help doctors, psychiatrists and psychologists to think about how best to support people with memory problems.

Why have you been chosen?

You have been asked to participate in this study because your [mother] has attended the [local service] for memory problems. For this study I will be talking to ten women and a family member. All these women will have attended a clinic for memory problems.

Do you have to take part?

You do not have to take part in this study if you do not want to. If you decide to take part you and your [mother] will be asked to sign a consent form. You may change your mind and withdraw at any time without having to give a reason. Your decision whether or not to take part will not affect the care you and your [mother] receive from the NHS in any way.

What will happen if you take part?

I would like to talk with you about your [mother's] past experiences and her current memory problems. The interview will last about 30 minutes and will take place at your home at a time that is convenient to you and your [mother]. The interview will be tape-recorded so that I can look back at our conversation and compare it with similar interviews that I have of other people who have a family member with memory problems. At the end of the interview you will be asked to complete a short questionnaire. The questionnaire will ask you about how your [mother] copes with everyday activities and will take about 15 minutes to complete. I also wish to interview your [mother] for about 45 minutes. I will ask her similar questions and she will also be asked to complete a short questionnaire.

What are the possible benefits or disadvantages to taking part?

These interviews are not part of your [mother's] treatment. Some people find it helpful to talk in confidence about their experiences and difficulties. Other people may feel upset by talking. I will try to be sensitive and not upset you or your [mother]. I hope that you will find the interview helpful and enjoyable. If you or your [mother] do feel upset by any my questions I can offer you support form your local psychology service, but I will only contact them with your permission.

All proposals for research are reviewed by the ethics committee before they can proceed. The [Local Research Ethics Committee] reviewed this research proposal.

Will taking part in this study be kept confidential?

All information that is collected about you during this research will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it. I will erase the tape-recordings after I have studied them.

What will happen to the results of this study?

I am a Trainee Clinical Psychologist at University College London. The results of this study will be presented in my thesis and in a paper that will be presented to a psychological journal for publication. It will not be possible for anybody to identify you in the published results. This research will take me about one year to complete. I will send you a short summary of the findings when the research is completed.

What will happen next?

Within the next few days I will contact you and your [mother] by telephone and arrange to make an appointment to meet with you. This will be an informal meeting during which you will have the opportunity to ask me questions about the study. If you then agree to take part in the study I will arrange another appointment to come and see you.

Thank you for your time in considering this study.

Mike van Dijkhuizen
Trainee Clinical Psychologist
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT
Tel 020-7490 5696 (answer machine)

**APPENDIX C
CONSENT FORM**

(Local Mental Health Trust Headed Paper)

CONSENT FORM

How do older women cope with memory problems?

Researcher: Mike van Dijkhuizen
Trainee Clinical Psychologist
University College London

Please complete by circling as appropriate

- | | | |
|---|-----|----|
| 1. I have read the information sheet about this study | YES | NO |
| 2. I have had an opportunity to ask questions and discuss this study | YES | NO |
| 3. I have received sufficient information about this study | YES | NO |
| 4. I understand that I am free to withdraw from this study at any time, without giving a reason and that this will not affect my NHS care | YES | NO |
| 5. I agree to take part in this study | YES | NO |
| 6. I agree to the interviews being audio-taped | YES | NO |

Signed: - _____

Please print name: - _____

Researcher's name: - _____

**APPENDIX D
FEEDBACK LETTER TO PARTICIPANTS**



Sub-Department of Clinical Health Psychology
UNIVERSITY COLLEGE LONDON
GOWER STREET LONDON WC1E 6BT

Tel 020-7490 5696 (answer machine)

Date
Name
Address

Dear Mrs

Re 'How do older women cope with memory problems?'

I am writing to give you a brief overview of the result of the above study in which you took part. I visited you some months ago and interviewed you about your memory problems. These interviews form part of my research thesis for my doctorate in clinical psychology. I had conversations with nine women with memory problems and family members. I listened to our conversations and wrote them out word for word. I carefully examined all the women's interviews and noted down examples of what they thought of their memory problems and how they managed their difficulties. The family member interviews were used to provide additional information. I would now like to give you a brief summary of my findings.

What the women thought about their memory problems.

Most of the women felt that their memory caused them some difficulties. Various explanations for memory problems were given. Some of the women thought memory problems were a normal part of getting older, whilst others thought stress and loneliness contributed to their problems. Other explanations included previous head-injury and Alzheimer's disease. Some of the women felt that memory problems affected their identity and connection with their past. Other women did not worry about their difficulties and said that they could manage.

How the women coped with memory problems.

1. Supportive family relationships

Most of the women talked about the role of family in helping them in their daily tasks, doing things together and reminding them to do things. Closeness to family was an important value and the ability of the women to maintain such relationships appeared to affect their well-being.

2. Friends and neighbours

Several women talked about the importance of maintaining contact with their friends and neighbours. However, other women worried about losing such contacts. This is of some interest as previous research indicates that women perhaps attach more importance to such relationships than men.

3. Maintaining valued activities

Several women talked about the importance to maintaining valued activities either within the family as a mother or grandmother, involvement in housekeeping, or outside the home by visiting friends. Memory problems meant that the women needed some help in maintaining their valued activities.

4. Routines and familiar surroundings

The women talked about the importance of routines and being familiar with their local area. For some women, established daily routines meant that they did not necessarily experience memory loss as a problem.

5. Memory was not so bad

Some of the women said their memory loss was not so bad because they still remembered things that were important to them, such as their family and events from their past. Other women knew they forgot things but thought that given time they would eventually remember again or someone else might jog their memory.

6. Humour

There was a lot of humour in the conversations. Some women commented that they enjoyed being interviewed.

7. Memory problems was not really an issue

Some of the women did not think memory problems were an issue for them. They said they did not worry about it, but instead focused on one thing at a time and preferred not to think or talk about it.

8. Just putting up with it

Several women mentioned that they accepted their difficulties and just put up with them. It seemed that a lifetime of experience had given them some strength in accepting their difficulties.

9. Memory problems are normal

Many women thought it was normal to be forgetful in old age. Some pointed out that their parents, friends and partners also had memory problems.

10. Problem solving

Staying occupied was mentioned as important and the women attempted to do this by going out and significantly many mentioned watching television. Some family members expressed concern about this. Practical ways of remembering things included writing things down, keeping things to hand and checking. The family was important in helping the women with problem solving. Some women mentioned how they benefited from medication.

This brief summary shows that there was great variety in what the women thought about their memory problems and how they managed their difficulties. The detailed results will be presented as my research thesis at the end of June 2003 and may later be written up for publication. I would like to reassure all those who took part that all names and identifying details have been changed to protect your confidentiality. If you would like to discuss these results further or wish to have a copy of any future publication please feel free to contact me.

Finally I would like to express my utmost thanks to you for taking part and making this project possible.

Yours sincerely,

Mike van Dijkhuizen
Trainee Clinical Psychologist

APPENDIX E

INTERVIEW SCHEDULES

Interview schedule for main participant

This semi-structured interview may take up to 45 minutes, but the length may vary according to the participant's preferences. Some interviews may therefore be considerably shorter. The aim is to enter the psychological and social world of the respondent. As such the order and wording of the questions will be flexible, allowing maximum opportunity for the respondent to tell her story. However, it is also important for the participant with mild cognitive impairment to be guided through the process. To orient the person to the interview a card will be displayed showing four main headings of the interview in large print. Broad questions may be followed by prompts, which will only be used if the person has difficulty understanding a question. Where appropriate, questions that are likely to elicit negative feelings are followed by questions about positive topics, experiences or achievements.

Talking about you and your past

- *"Where did you spend your childhood?"*
- *"Can you tell me about your education?"*
- *"What did you do after you left school?"*
- *"When did you meet (husband/partner)?"*
- *"Do you have any children?" if no "Would you have liked to have children?"
if yes "Tell me about your children? grandchildren?"*
- *"Looking back over the years, tell me about something that's happened to you that was upsetting or difficult for you?"*
- *"Now tell me about something you have done that you are proud of?"*
- *"What kind of things do you enjoy doing?"*

Talking about what you think about your memory problems

- *"Tell me how did you come to be seen at (the memory clinic)?"*
- *"What do you think is happening to you?"*
- *"What does the doctor/clinic say is happening to you?"*
- *"What do you think about that?"*
- *"Do you talk to (husband/carer) about this?" ... "What does s/he say?"*
- *"Do you take any medication for your memory problems."
If yes "What does the medication do?"*

Talking about the daily difficulties of memory problems

- *"Tell me about the main problems you experience due to your memory difficulties (Alzheimer's disease if mentioned)?"*
- *"How does it affect the everyday things you need to do?"*
- *"How does it affect your... (hobbies, interests, activities mentioned in background)?"*
- *"How does it affect the way you carry out your responsibilities as a...(social roles mentioned by participant e.g., homemaker, grand/parent, carer etc)?"*
- *"Do you and (husband/carer) get any help?"*

Talking about how you manage these difficulties

- *"When (problem mentioned above) happens, what do you do?"*
- *"Is there anything that helps with...(identified problem)?"*
- *"Are there things that make it worse?"*
- *"How does (husband/carer) help you?"*
- *"Do you worry about the future?"*
- *"Now tell me about something you look forward to?"*

Interview schedule for partner/carer

Background

Summarise what the woman has told you and if necessary use the following prompts

- *"Can you tell me about (your wife's) education?"*
- *"What did she do after she left school?"*
- *"Looking back over the years, how do you think she coped in the past with difficult or upsetting events?"*
- *"Tell me about something she is proud of?"*
- *"What kind of things does she enjoy doing?"*

Perceptions of Alzheimer's disease.

- *"Tell me how did she come to be seen at (the memory clinic)?"*
- *"Who first noticed there were problems?"*
- *"What do you think is happening to her?"*
- *"What does she think is happening to her?"*
- *"How did she react (to the diagnosis of Alzheimer's disease)?"*
- *"Do you talk about this?"*
- *"Does she take any medication for her memory problems (Alzheimer's disease)?"*

If yes *"What does the medication do?"*

Effects of Alzheimer's disease

- *"Tell me about the main problems she experiences due to memory problems (Alzheimer's disease)?"*
- *"How does it affect her daily routine?"*
- *"How does it affect her (hobbies, interests, activities mentioned above)?"*
- *"How does it affect her ability to carry out her responsibilities as a ...(social role)?"*
- *"Do you and (main participant) get any help?"*

Dealing with the problems

- *"When (problem mentioned above) happens, what does she do?"*
- *"Is there anything that helps with.....?"*
- *"Are there things that make it worse?"*
- *"Are there things you do to help her with her memory difficulties?"*
- *"Does she worry about the future?"*
- *"How do her difficulties affect you?"*
- *"What kinds of things help you to deal with this?"*