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Caregivers' experience of their spouse's coping style in dementia: a study using Interpretative Phenomenological Analysis

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This thesis is submitted in partial fulfilment of the degree of Doctor of Clinical Psychology

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July 2011

Word Count: 19,928 (excluding abstracts, references, appendices and footnotes)

General Abstract

Within the field of dementia research there is much in the literature on caregiver burden and stress, whilst there is comparatively little on the coping experiences of the person with dementia. The majority of individuals with dementia are currently cared for in the community and research has focused on the factors implicit in caregiver burden and started to identify characteristics which may place individuals at risk of higher levels of strain and distress. Qualitative research has started to investigate the experience of dementia from the patients' perspective. However the interaction between the two has been largely neglected in the empirical field.

The first section of this thesis is a literature review detailing the current available research on the psychological wellbeing of informal caregivers for people with dementia, the coping style favoured by caregivers, and the coping experiences of people with dementia.

The second section of this thesis is a qualitative study which seeks to explore and understand the interaction between eight caregivers and their spouses with dementia. Interpretative Phenomenological Analysis was used to analyse interviews with the eight caregivers and to produce themes which were salient for participants. The findings are discussed within the wider research context whilst clinical implications and possibilities for future research are acknowledged.

Contents

Acknowledgements

I would like to thank my supervisors Dr Ann Marshall and Professor Peter Coleman for their help, support and advice throughout the development of this project. I would also like to thank the Memory Group at The Dovetail Centre, Eastleigh and Annie Bea for their help in facilitating the recruitment of participants for this study. My thanks also go to Mark Walker for proofreading the drafts of this thesis. Finally I would like to thank the participants who gave up their time and shared their experience in order that this study could be completed.

Literature Review Paper

An Exploration of the Factors Affecting Psychological Wellbeing in Caring for People with Dementia and the Coping Response of the Dementia Sufferer.

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Running Head: The Experience of Caring for People with Dementia

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American Psychological Association publication guidelines have been applied, as if for submission to *Dementia*.

Abstract

This literature review critically discusses the current available literature regarding the coping experiences of people with dementia and the wellbeing of their caregivers. As the prevalence of dementia has increased in recent years so too has the research interest in this area. Given that the majority of individuals with dementia are now cared for in the community, it is important to recognise the levels of stress experienced by informal caregivers and the impact that caring has on their psychological and physical wellbeing. Research has focused on the factors implicit in caregiver burden and started to identify characteristics which may place individuals at risk of higher levels of strain and distress. Qualitative research has also investigated the experience of dementia from the patients' perspective. Models of coping have been proposed which suggest that it is characterised by balancing the tension between wishing to maintain an existing or prior sense of self, and the need to reappraise and reconstruct a sense of self in the light of changes in cognitive, social or environmental factors (Clare, 2002c). However there is still very little in the literature on how the models of coping utilised by the person with dementia impact on the level of stress experienced by the caregiver. This important area requires further research attention.

Introduction

Advances in health care have resulted in people living for longer. Since the 1930s the number of people aged over 65 has more than doubled and currently 20% of the population is aged over 60. It is estimated that between 1995 and 2025 the number of people over the age of 80 is set to increase by over 50% and the number of people over 90 will double (Department of Health, 2001). This increase in individuals in the older age range has led to an increase in the prevalence of dementia. Dementia is a progressive and largely irreversible clinical syndrome that is characterised by widespread impairment of cognitive function. It is associated with memory loss, language impairment, impaired executive functioning, loss of abilities to perform activities of daily living and progressive deterioration in functional skills (National Institute for Health and Clinical Excellence, 2006; World Health Organisation, 1992).

The majority of people with dementia are cared for outside institutions, mainly by the family, and many families prefer to care for a relative at home though the demands may be considerable (Braekhus, Oksengard, Engedal, & Laake, 1998; Zarit, 2008). The literature reflects the fact that caregiving is associated with higher levels of depression, anxiety, anger, and mortality (Ballard et al, 1995; McConaghy & Caltabiano, 2005; Zarit, 2008). Much research has focused on caregiver burden and the factors which are likely to exacerbate the stress experienced by caregivers. Research has also focused on the coping strategies adopted by individuals with dementia. A common theme noted in studies of coping in dementia is the tension between preserving skills and independence whilst attempting to cover up accumulating losses (Clare, 2002c).

This literature review is concerned with the research on the psychological wellbeing of informal caregivers for people with dementia, the coping style favoured by caregivers, and the coping strategies utilised by individuals with dementia. There is much in the literature on caregiver burden and stress, whilst there is comparatively little on the coping experiences of the person with dementia. The majority of the research in the area of how patients cope with dementia is qualitative and gives a rich account of the individuals' experiences. However the limitation of qualitative research is its lack of generalisablity. In summation, this review will focus on the available literature regarding caregiver coping, patient coping, and the interaction between the two. This review will offer a descriptive and critical account of the current literature with reference to areas requiring further research.

Methodological Approach

This literature review utilises a narrative approach and generates a qualitative overview of the literature relating to the experiences of caregivers for people with dementia, and the individuals with dementia themselves. A narrative approach adopts a 'story-telling' format and best supports the available literature in this area. It reflects an interpretation of the literature based on theories, models and research.

Searches for relevant literature and resources were undertaken using the databases *PsycInfo*, *PsycArticles* and *Web of Knowledge*. Keywords in various conjunctions were used to identify articles. These search terms included: dementia, carer, caregiver, coping style, caregiver burden, caregiver stress, Alzheimer's disease. These searches returned numerous resources which the researcher then examined for relevance by reading and appraising the abstracts of the articles. It is noted that a difficulty of an international review of the literature is that there may be significant differences in the nature of community and residential care in different countries.

Background

Due to the fact that people are living longer, the prevalence of dementia has increased with more people diagnosed in the early stages and living longer in severe stages with better healthcare (Cohen, 2000). There are estimated to be over 750,000 people in the UK with dementia and numbers are expected to double in the next thirty years (National Dementia Strategy, 2010). As life expectancy continues to increase, more people are expected to live into the higher risk age categories for dementia. In addition, if the number of therapies aimed at slowing the progression of dementia continue to increase then it is likely that more people will remain for longer in the early stages of the disease. Independent living is still possible in this early stage of dementia but memory loss interferes with the more complex activities of daily living and with work and social activities (Steeman, Godderis, Grypdonck, De Bal, & Dierckx De Casterle, 2007).

The concept of caregiving has progressed from the notion that it is concerned primarily with practical matters such as meeting basic needs, provision of a safe environment and competent physical care. The new culture of caring is primarily concerned with the maintenance and enhancement of personhood and views practical care as only part of the caregiving role (Kitwood, 1995). The majority of people with dementia are cared for at home by a spouse or relative (Cohen, 2000; Zarit, 1999). The caring role is known to be arduous and much research has shown that caregivers suffer from high levels of stress and psychological morbidity. The literature acknowledges that caregivers endure an impaired social life, degrees of social isolation, reduced employment prospects, and extreme tiredness and exhaustion. Decreasing length of hospital stays and decreased coverage for home health services have also resulted in caregivers taking on tasks (such as provision of intravenous medications, bladder catheters, managing home oxygen) that were previously performed by health care professionals (Zarit, 2004). However, despite the considerable demands, many families prefer to care for a relative at home (Zarit, 2008).

Audit Commission Findings

Support from services is vital for caregivers given that the majority of people with dementia are cared for by family at home. However, the audit commission (2002) found that 75% of areas audited in England lacked good written information about local services. Encouragingly, the audit commission found that nearly all caregivers questioned were told what was wrong with their relative and two thirds were told how dementia would develop. It is important that all these areas are addressed so that all caregivers have up to date, accurate information about their loved ones' condition and details of resources and services available. Indeed, the National Service Framework (Department of Health, 2001) states that treatment of dementia *always* involves explanation of the diagnosis to the older person and caregivers, dissemination of relevant information about resources, and information about prognosis and packages of care available. From the perspective of the professional, the audit commission found that many GPs felt that they needed more support due to limited specialist support and training (Audit Commission, 2002).

National Service Framework (Dept of Health)

A newfound respect for older people has emerged over recent decades and the Department of Health (2001) has recognised that the individual needs of older people should be considered. In addition, improving the quality of care for people with dementia and their caregivers is a major priority under the new Coalition Government. Psychological research often includes the thoughts and opinions of individuals experiencing pathological conditions and those of their caregivers. The involvement of service users in care planning and service development is encouraged in line with government directives which state that service users are actively sought out and engaged (Department of Health, 2001). However, despite such directives, the views of individuals with dementia appear to be underrepresented. This is particularly important given that research has suggested that the views of professionals and caregivers are not necessarily in accordance with the individual with dementia (Goldsmith, 1996; Whitlatch, 2001). Similarly, Wilkinson (2002) has emphasised the importance of engaging dementia sufferers in research and states that recognition of their views is "an ethical and moral underpinning on which dementia research can move forwards" (Wilkinson, 2002; p.20).

NICE guidelines for supporting caregivers of people with dementia

The National Institute for Health and Clinical Excellence (NICE) recognises that dementia is associated with complex care needs which can often challenge the skills and capacity of caregivers and services. The guidelines state that where possible and appropriate, agencies should work in an integrated way in order to maximise the benefits for both people with dementia and their caregivers. These guidelines draw from the Caregivers and Disabled Children Act 2000 and the Caregivers (Equal Opportunities) Act 2004 to ensure that caregivers receive an assessment of their needs as an ongoing process. The purpose of the assessment is to identify any psychological distress and psychosocial impact on the caregiver and NICE recommend individual psychological therapy, including cognitive behavioural therapy, in this eventuality. The NICE guidelines recommend a range of tailored interventions be addressed in the care plans of caregivers of people with dementia; individual or group psychoeducation, peer support, access to telephone and internet resources, and involvement of family members in addition to the primary caregivers. The NICE guidelines also focus on the practical aspects of care such as access to respite services which are characterised by meaningful and therapeutic activity (NICE, 2006).

Caregiver Burden

Caregiver strain

The literature shows that family members play a major role in the care of elderly people with dementia with approximately 80% being cared for at home (Cohen, 2000; Leggett, Zarit, & Taylor, 2009; Gilhooly, Sweeting, Whittick, & McKee, 1994; McConaghy & Caltabiano, 2005; Whitlatch, 2001; Wijeratne, 1997). Wijeratne (1997) found that the majority of these caregivers tend to be wives or daughters who are aged 60 years or older. The concept of caregiver burden first came to attention in the 1970s when Fengler and Goodrich (1979) identified caregivers as 'the hidden patients' due to the impact on their own physical and psychological health. The concept of caregiver burden has been operationalised in different ways in the literature and has received definitions ranging from Brown's (1967) 'the impact of living with a patient on the way of life and health of his or her significant others" to Zarit's (1986, 2008) acknowledgement that burden is "the degree to which a caregiver's emotional or physical health, social life or financial status had suffered as a result of caring for their relative". What is consistent in the literature is that caregiver burden or stress is a wide ranging phenomenon which impacts on all areas of the caregiver's life.

Caregiver burden or stress manifests itself in a variety of ways; psychological, physical, and economical. Zarit (2004) found that between 40 % and 70% of caregivers have been found to have clinically significant levels of depressive symptoms with 50% meeting criteria for a diagnosable depressive disorder at some point during their period as a caregiver. Research in this area has produced similar figures (Ballard et al, 1995; Cohen, 1991; Gilhooly et al, 1994; Saad et al, 1995; Wijeratne, 1997). In addition to depression, caregiving has been found to be associated with higher levels of anxiety and anger. The physical impact of the chronic stress of caregiving has been found to lead to changes in immune system functioning, hormone levels, higher rates of cardio-vascular disease and other medical complaints, and increased risk of mortality when compared to age and gender matched controls (Zarit, 2008). Compared to non-dementia caregivers, Cohen (2000) found that twice as many dementia caregivers took early retirement, gave up working, lost job benefits, experienced financial hardship and turned down promotions in addition to experiencing work disruptions and family conflict. However, work can be seen as a buffer to the role of caring for a loved one with dementia and may provide valuable respite and time-out from the stressors of caregiving (Zarit, 2008). The exception to this is when the caregiver believes that their work performance has been compromised as a result of the caregiving role (Wijeratne, 1997). Caregivers have also been found to be more likely to use psychotropic drugs and to rate their self-related health as poorer than that of comparison groups (Andren & Elmstahl, 2008). Much of the research on caregiver stress has involved caring for people with moderate to severe dementia. Braekhus, Oksengard, Engedal and Laake (1998) investigated caregiver burden and mild dementia and found that spouses of people with mild dementia also expressed frequent symptoms of stress.

Caregiver characteristics implicated in caregivers stress

Certain characteristics of the caregiver have been found to be predictors of strain. Women have been consistently found to experience more stress than male caregivers and caregivers with higher education report more emotional strain (Boutselis & Zarit, 1984; Cohen, 2000; Wijeratne, 1997). Daughters and daughters-in-law have been noted to exhibit greater distress than spousal caregivers by Wijeratne (1997) whilst in contrast Boutselis and Zarit

(1984) had previously found that whilst sons reported higher burden than husbands, there was no difference between wives and daughters. Ballard et al (1995) found in their study that if caregivers were a spouse or first degree relative, had lower levels of premorbid marital intimacy or were increasing in age then the levels of stress were found to be higher. These findings have also been yielded in other studies (Ballard et al, 1995; Zarit, 1982; Zarit, Todd & Zarit, 1986). It has been hypothesised that women show greater emotional over-involvement, are less able to take a step back from the caregiving role and subsequently find it harder to obtain the occasional moment of respite, resulting in greater psychological distress. In addition, women may find the physical aspects of caregiving harder than men, whilst for men the role of caregiver may be a novel one (Gilhooly et al, 1994; Wijeratne, 1997). Interestingly female caregivers tend to have more social supports than male caregivers, and social support is known to mediate the effects of caregiver burden (Gilhooly et al, 1994; Zarit, Reever, & Bach-Peterson, 1980).

Caregivers who are less secure and display a more avoidant attachment style have been found to report higher levels of anxiety (Cooper, Owens, Katona, & Livingston, 2008). The researchers hypothesised that these caregivers would be more likely to utilise dysfunctional coping strategies and unhelpful ways of coping which increased feelings of burden.

Level of Cognitive Impairment

The level of cognitive impairment has not been found to be related to the degree of burden experienced by caregivers. Studies have found that it is the non-cognitive features of dementia such as behavioural disturbances, psychotic symptoms and depressive features which are perceived as more stressful by caregivers (Ballard et al, 1995; Gilhooly et al, 1994;

McConaghy & Caltabiano, 2005). Research also shows that these acts of commission, where a person exhibits features which they previously did not, are more stressful for caregivers than acts of omission such as inability to get dressed, bathe, or prepare a meal (Gilhooly et al, 1994). In addition, caring for a person with dementia over a long period of time has been found to be associated with decreased levels of caregiver burden (McConaghy & Caltabiano, 2005). It is hypothesised that the middle stages of dementia are the hardest to care for due to the level of behavioural disturbance and that as the condition progresses it becomes easier to care for and consequently leads to less burden (Gilhooly et al, 1994). The caregivers in Zarit, Todd and Zarit's 1986 study stated that over time they had learned to manage problems more effectively and that they simply did not let problems bother them anymore.

Cultural factors

Wijeratne (1997) has cited cultural factors as exacerbating the difficulties experienced by caregivers. He postulates that most people living in industrialised countries have little direct exposure to chronic illness and death due to declining medical morbidity and mortality. Consequently caregivers of people with dementia may feel unprepared for their role. In addition, he states that the stigma associated with the psychiatric complications of dementia such as psychosis can be another source of difficulty and strain.

Anticipatory grief

It has been suggested that caregivers experience feelings similar to anticipatory grief which contributes to the experience of burden (Gilhooly et al, 1994). Gilhooly et al, 1994, state that the losses within the relationship such as intimacy, cognitive and physical changes can lead to the caregiver grieving for the relationship.

The Stress Process Model of Caregiving

Pearlin, Mullan, Semple and Skaff's (1990) model of caregiving stress views burden as a multidimensional process rather than a single entity and represents the components which result in psychological and physical strain. The model comprises four domains contributing to caregiver burden: the background and context of stress, the primary and secondary stressors and strains, the mediators of stress, and the manifestations/outcomes of stress. This model can be seen in Figure 1.

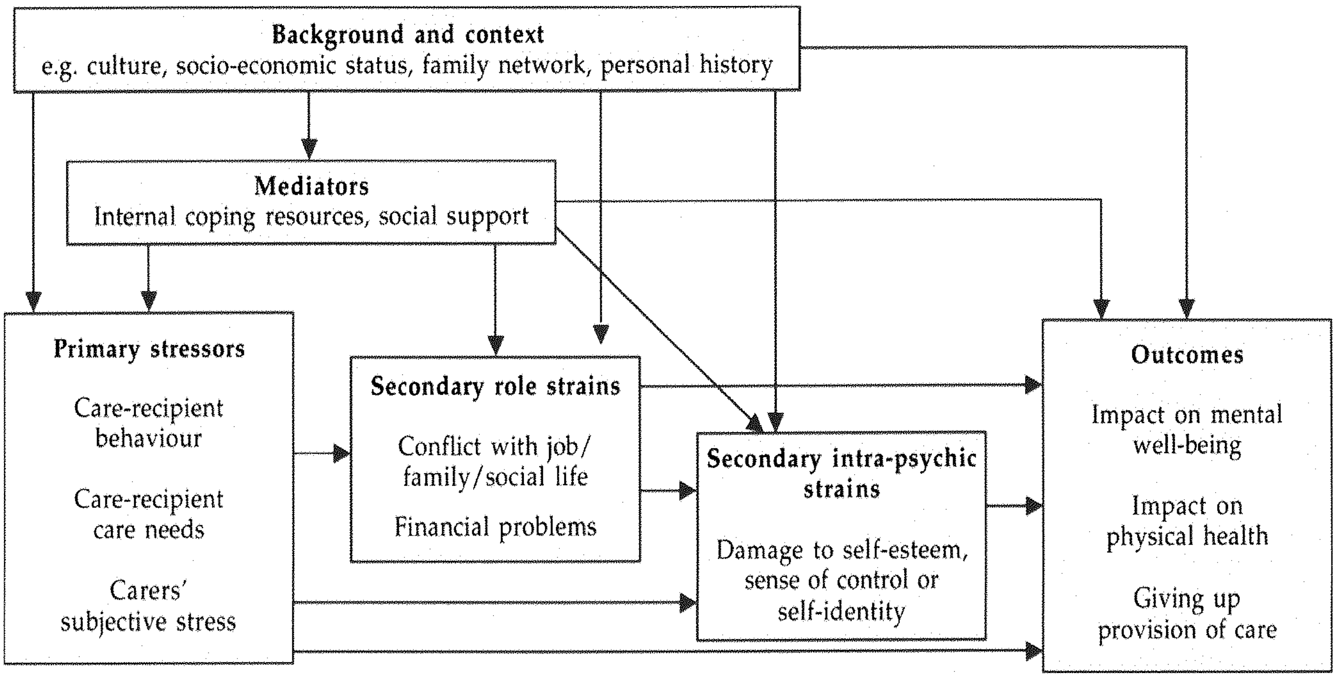
The background and context of the stress process model takes account of the predisposing factors and includes gender, age, family network, culture. Research has shown that factors such as being female, low premorbid marital intimacy, increasing age make it more likely that the caregiver will experience psychological distress (Ballard et al, 1995; Cohen, 2000; Zarit, 1982; Zarit et al, 1986).

Primary and secondary stressors differentiate between objective and subjective stressors. Objective primary stressors include disease characteristics and symptoms such as memory or behavioural problems, whilst subjective primary stressors are the extent to which the specific problems are experienced as stressful. This is an important distinction because whilst dementia creates the conditions which can be experienced as stressful, the extent to which caregivers feel burdened by these demands varies considerably and it is this subjective meaning that has been found to be a strong predictor of caregiver burnout (Zarit, 2008). Secondary stressors are very challenging for caregivers and are the extent to which care demands interfere with work or personal responsibilities.

The mediators of stress are the individual differences in response to stress that make up active efforts to cope with the burden of caring for a loved one with dementia. Access to social support, individual coping style and input from services are mediators of stress. Emotional support provided by friends and relatives is often critical for the caregivers' wellbeing.

Outcomes or manifestations of stress are the symptoms of burden that are experienced by caregivers. This model illustrates that a mixture of circumstances, experiences, responses and resources that vary among caregivers consequently varies in the impact of the psychological and physical health of the caregiver.

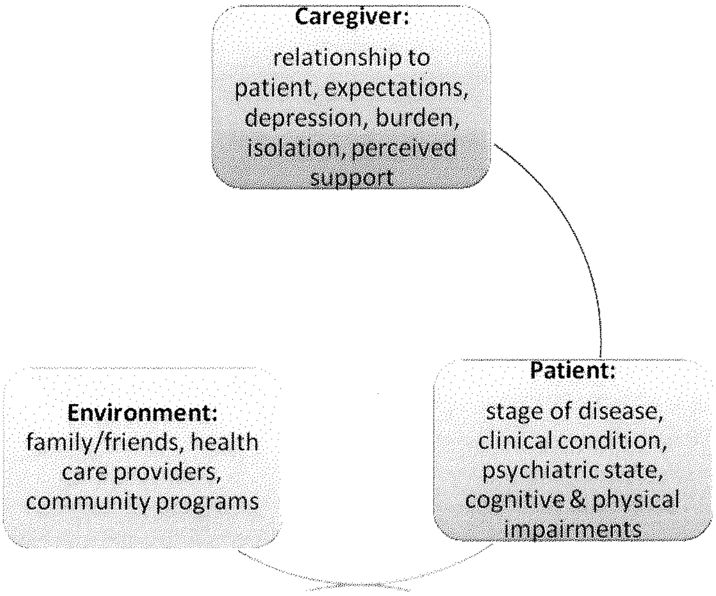
Figure 1. Pearlin et al's Stress Process Model of Caregiving (1990)



The REACH system model of the dementia caregiving system

This model of the dementia caregiving system was proposed by Eisdorfer (cited in Cohen, 2000) at the Las Vegas meeting for the Resources for Enhancing Alzheimer's Caregiver Health (REACH) collaboration in 1999. This model can be seen in Figure 2 and depicts caregiving as a complex process in which changes in the components (patient, caregiver, family, and environment) interact with each other to mediate negative and positive outcomes for the patient, the caregiver and the family. The model consists of a caregiver-patient-environment cycle in which factors associated with each component affect one another. This model has much in common with Pearlin's model in terms of the multidimensional process of caregiving. However, this model has received criticism for locating the family in the environment component of the model rather than specifying it as a separate and fourth element (Cohen, 2000).

Figure 2. REACH interactive model of the dementia caregiving system



Management of burden

It is important that the level of demand and stress placed on caregivers is recognised because they are an essential part of the treatment team for patients with dementia (Zarit, 2004). The research suggests that in terms of intervention and management of caregiver burden, it is more important to support the wellbeing of the caregiver rather than address specific solutions to remedy the behavioural or memory problems of the patient with dementia (Zarit et al, 1980).

Chappell, Reid and Dow (2001) identified a mismatch between the needs of caregivers and service provision. They found that most caregivers placed a high priority on the emotional aspects of caring whilst service providers emphasised the provision of practical assistance.

Groups/ Interventions for Caregivers

Early intervention is important in supporting caregivers. A 1995 study (Commissaris, Jolles, Verhey, & Kok) found that caregivers who received professional help in the early stages of dementia experienced fewer problems in providing care at a later stage. These findings confirm the importance of early detection and diagnosis of dementia. Day care for dementia sufferers has been found to offer some respite to caregivers. Curran (1995) found in her study that 92% of the caregivers interviewed reported that day care services have brought some improvement to their lives, while half of these respondents stated that it had made a great deal of difference to them. The break that day care services afforded allowed caregivers to carry out everyday activities such as shopping, visiting friends, and attending personal appointments.

Zarit (2008) identified that in terms of management of burden, interventions for caregivers tend to focus on three areas: psychoeducation, behavioural strategies, and building family and paid support. He stated that education groups for caregivers are vitally important to consolidate information. Caregivers are often under a great deal of stress when they seek help and may not ask the questions that are most pressing and therefore may be compromised in terms of how much they are able to retain. Zarit (2008) recognised that the support which caregivers receive is a critical component in managing caregiver burden and that respite is important in maintaining the psychological and physical wellbeing of caregivers. He also identified the family meeting as an effective intervention which serves several purposes. The meeting aims to lead to a better understanding of dementia among the family which in turn hopefully leads to an increase in the assistance and support they are willing to give.

A review of previous studies into the effects of groups for caregivers (Morris, Woods, Davies, Berry, & Morris, 1992) found that education groups and problem solving groups produced positive results in terms of caregivers' increased use of problem solving strategies, emotional involvement in caregiving and improved knowledge. However, there was little change observed in levels of stress and depression although caregivers stated that they had found the ability to vent their emotions helpful. Conversely, a 2005 service evaluation undertaken by Hoskins, Coleman and McNeely found that the outcome of the Community Mental Health Team intervention they reviewed provided evidence that such health care provision is effective in reducing levels of caregiver stress. This is just one study however and the results therefore need to be interpreted with caution.

Caregiver Coping

Coping has been defined as "the things people do (acting or thinking) to increase a sense of well-being in their lives and to avoid being harmed by (potentially) stressful events" (Turnbull and Turnbull, 1993). Evidence suggests that caregivers frequently adopt a process of trial and error and try out a number of solutions until they find the one that works and over time caregivers build up an extensive repertoire of coping skills (Nolan, Ingram, & Watson, 2002).

Impact of knowledge on caregiver wellbeing

Graham, Ballard and Sham (1997) investigated the impact that knowledge has on caregiver coping. They found that caregivers with greater knowledge experienced significantly lower rates of depression than caregivers who were less well informed. Graham et al hypothesised that depressed caregivers may be less likely to seek out knowledge due to apathy and social withdrawal. Equally, increased knowledge may have a causal effect on decreasing depression. However, more knowledgeable caregivers were also found to have significantly higher rates of anxiety. The researchers hypothesised that anxiety may have increased due to the caregivers' anticipation of the losses associated with the progression of dementia. Equally, anxious caregivers may be more likely to seek out knowledge.

A similar study by Proctor, Martin and Hewison (2002) found that increased knowledge led to higher levels of anxiety when the information was bio-medical, thus heightening caregivers' anticipation of losses as dementia progresses. Proctor et al hypothesised that where information is vague and does not lead to greater control over the situation, vulnerability to anxiety increases. The literature suggests that in times of stress there are individual preferences for knowledge with some individuals preferring increased access to information and others avoiding information (Proctor, Martin, & Hewison, 2002).

Sense of Coherence

Andren and Elmstahl (2008) have investigated sense of coherence (SOC) as an explanation of successful coping in caregiving. They recognised that the way an individual interprets events is crucial to whether they become stressed or not. SOC, first identified by Antonovsky in 1987, expresses the extent to which individuals have a pervasive, enduring though dynamic feeling of confidence that: (1) the stimuli deriving from internal and external environments in the course of living are structured, predictable, and explicable, (2) the resources are available to meet the demands posed by these stimuli, and (3) these demands are challenges, worthy of investment and engagement (Antonovsky, 1993). Essentially these three components are comprehensibility, manageability and meaningfulness. It is known that caregivers with a low SOC have worse health, lower quality of life and a smaller social network (Andren & Elmstahl, 2008). In the present study, Andren and Elmstahl (2008) found that the relationship between burden and perceived health was influenced by coping strategy (measured by SOC). Individuals with a strong SOC had greater coping capacity for choosing adaptive successful coping strategies. Conversely, a low SOC in the caregiver leads to the situation being perceived as less comprehensible, harder to manage, less meaningful, with fewer resources to adapt to the caregiving situation, resulting in greater levels of burden being experienced. The researchers concluded that the use of a scale identifying SOC is highly useful for identifying caregivers at risk of stress.

Coping styles

Coping styles have been shown to be important mediators of stress and depression amongst caregivers of dementia sufferers (Pearlin, Mullan, Semple, & Skaff, 1990; Saad et al, 1995). Coping style has been hypothesised to be a mediator in caregiver stress. Williamson and Schulz (1993) identified *active* and *passive* coping strategies. Actively seeking out resources such as social support is associated with lower levels of psychological distress. Passive strategies such as stoicism and wishfulness are correlated with greater depressed affect.

A study by Cooper, Katona, Orrell and Livingston (2008) found that caregivers who used emotion-focused coping strategies (acceptance, emotional support) were less anxious at one year follow up, whilst those who engaged in problem focused strategies were more anxious. Caregivers who utilised dysfunctional coping strategies (denial, disengagement) remained similarly anxious at follow-up to baseline.

Caregiver Profiles

In their 1992 research, Cairl and Kosberg identified distinct clinical profiles of caregivers. The caregivers in their study were receiving adult day care or in-home respite care services and presented as a homogenous group. Cairl and Kosberg were interested to see the relationship between caregiver burden and caregiver competence and examined the extent to which they sought knowledge and formal support, provided for the medical/nursing needs, safety needs, social needs, and personal care needs for the individual for whom they were caring. The researchers identified four clinical profiles which were distinguished by caregiver background and status, and patient status.

The *Intolerant* subgroup were characterised by caregivers who were more likely to be working, satisfied with their level of social support, have greater quantity of informal support, less tolerant of the behavioural impairments of the person in their care, and to be caring for a patient with lower levels of cognitive and behavioural impairment. Cairl and Kosberg hypothesised that this group had limited motivation and viewed the role of caregiver as an inconvenience. They suggested that interventions should be aimed at improving their skills and their understanding of dementia.

The *Ideal* subgroup were characterised by caregivers with higher levels of social interaction, greater quality in their past personal relationship with the patient with dementia, a higher value investment in caregiving, and more positive self reported mental and physical health. The researchers hypothesised that this subgroup may not need interventions targeted at them, or minimal intervention only to enable them to sustain their stable status.

In contrast, the *Clinically Challenging* subgroup were identified as more likely to be working, to have less formal support, lower self-esteem, greater levels of psychopathology, and more negative self reported mental health. Formal intervention for this subgroup should be a priority and targeted at skills training and referral for respite services. Individual or group counselling services may also be useful.

The *Paradoxical* subgroup were characterised by caregivers with more formal support, greater tolerance for the behavioural impairments of the person in their care, greater perceived difficulty in caregiving, more likely to express negative self reported mental health, greater levels of pathology, to have been a caregiver for a longer period of time, and to be caring for a patient with a greater level of cognitive impairment. The researchers suggested that caregivers in this situation may benefit from emotional counselling to enable them to reach a decision about how long they are able to maintain being the full-time caregiver for their patient.

Cairl and Kosberg queried whether formal services are effectively prioritised to meet the needs of caregivers. It is important to recognise the differences between caregivers in terms of their profile in order to ensure that the services they are receiving appropriately target their needs and ensure effective formal service intervention.

Barriers to Support for Caregivers

Whilst the need for community based support for caregivers has been proven (Cohen, 2000; Curran, 1995), and research has started to evaluate the efficacy of these services, it is important to identify the factors which support or present barriers to their use. Qualitative research by Bruce and Paterson (2000) in Australia revealed contact with health agencies was the third most frequently reported source of stress by caregivers in their study.

The respondents in Bruce and Paterson's (2000) study identified the interaction between themselves and their GP as a barrier to accessing community support. Caregivers either failed to discuss their problems with their GP, the GP failed to perceive the extent of the difficulties, or the GP did not perceive community care as valuable and effective. Delayed referrals were also identified as barriers to accessing community support in addition to the lack of a definite diagnosis of dementia and lack of understanding of the diagnosis. Earlier referrals and psychoeducation to enhance caregivers' understanding would hopefully reduce levels of caregiver stress and improve the care of the dementia sufferer.

Whilst the results of this study are interesting, it has several limitations. Firstly, as with all qualitative research, it can be difficult to know whether the findings can be generalised to other groups or situations. Secondly, only 24 of the 62 caregivers approached actually took part in the interviews. The caregivers who declined to be interviewed stated that they were too busy or stressed to take part in the study and therefore this very stressed subgroup may not have been adequately represented in the study. This study also relied solely on the perceptions of the caregivers and it is just one study. Finally, this research took place in Australia, and its findings may not be generalisable to caregivers in England.

Coping Response of the Person with Dementia

It is interesting to consider the coping style of the person with dementia and any potential impact this may have on the level of stress experienced by the caregiver. Theories of coping define coping as a process in which individuals use cognitive or behavioural methods in order to manage internal or external demands which are perceived as exceeding the individual's resources (Lazarus & Folkman, 1984; Lazarus, 1993). Coping is perceived as a developing process and in terms of dementia, coping changes as neurological impairment progresses.

Interviews with people in the early stages of dementia have revealed that sufferers may try and cover up their initial memory lapses. Respondents often spoke with a sense of personal achievement when describing their successes in covering up early symptoms. They described utilising a number of strategies such as keeping notes, making up excuses, and withdrawal from social and stressful situations (Keady & Nolan, 1995a). Some research has identified coping as falling into two distinct styles; problem centred or emotion centred (Nery de Souza-Talarico, Chaves, Nitrini, and Caramelli, 2008), whilst other research has identified a broader spectrum of coping (Clare 2002, 2003, 2006).

Whitlatch (2001) found that if the person with dementia's involvement in decision making increased, their self-reported quality of life increased and depression decreased. The opposite effect was found for the caregivers; their depression increased and their quality of life decreased. Whitlatch suggested that caring for someone who takes an active role in decision making was problematic for some caregivers and that taking complete control over their care may be less stressful.

Personality types

Within psychiatry, the differences experienced from person to person with dementia have been considered by Jacques (1988). He identified six main personality types on the basis of his clinical experience. *Dependent* personality types were described as readily accepting of help with some reluctance to take the initiative and stand on their own two feet. *Independent* types favour feeling 'in charge' of situations and may resist facing the truth about their condition. *Paranoid* personality types easily resort to suspicion and blame whilst *obsessional* types experience self-doubt and fear the loss of order and control. *Hysterical* personality types may be demanding and attention seeking whilst the small minority of *psychopathic* types tend to be impulsive and lack concern for others. Jacques states that there are also normal personality types which have tendencies towards his six types.

Kitwood (1997b) stated that individuals clearly differ in the extent to which they are able to cope with the impact of dementia on their cognitive abilities. The coping style they adopt is likely to be influenced by their personality and past experience. Through this experience they will have built up preferred ways of handling difficult or stressful situations. Some people are more able than others to seek comfort and support whilst others may have stronger defences against acceptance and recognition of the illness. Kitwood suggests that only a minority of dementia sufferers are able to face their illness without high defences. He looked at six main personality clusters of dementia sufferers identified by Buckland in 1995. Buckland studied 132 people with dementia in residential care and identified the following personality clusters; anxious-passive (30% of sample), stable-amiable-routine loving (28%), emotional-social-active (26%), emotional-withdrawn-passive (8%), stable-outgoing-industrious (4%), and emotional-outgoing-controlling (4%). Kitwood (1997b) stated that the use of these personality types provides a glimpse of the variability of the dementia experience. Kitwood has drawn parallels between the personally types suggested by Jacques (1988) and Buckland and suggests that Buckland's anxious-passive type resembles Jacques dependent type. It follows that different personality types will be likely to have different styles of coping with dementia.

Identity

Harris and Sterin (1999) conducted in-depth interviews with individuals in the early stages of dementia in order to ascertain their concept of self and perceived identity. They identified three core themes in the interviews which defined how identity was perceived. These themes were reasonable autonomy, meaningful activities and productivity, and need for comfort and security. The participants in this study accepted that dementia would eventually rob them of their independence and they wanted to participate in decisions about themselves and others for as long as they could. Being productive was important to them. These findings link to Whitlatch's (2001) later observations that the more active dementia sufferers were in terms of decision making, the lower their levels of depression and better their quality of life.

Coping styles

In 2006, qualitative research by Preston, Marshall and Bucks revealed three major themes related to coping with dementia; *managing identity in relation to dementia* was identified as a coping task which focused on identity and was a means of actively managing dementia. The discontinuity between the past and present self was mediated by integrating the disease with their pre-existing sense of self and developing new skills and ways of being. The theme *making sense of dementia* was identified as participants managing their difficulties through making sense of them and viewing them as less cognitively threatening. The third major theme identified, *coping strategies and mechanisms,* involved coping in relation to others, everyday individual strategies, and personal attitude. Broadly, the coping mechanisms identified encompassed active cognitive and behavioural methods, more passive methods in relation to seeking support from others, and differences within personal attitude in terms of acceptance or fighting the disease.

Research by Nery de Souza-Talarico, Chaves, Nitrini and Caramelli (2008) identified two distinct styles of coping; problem centred and emotion centred. They described problem centred coping as attempts by the person to modify the problem. Emotion centred coping was described as attempts to regulate the emotional impact of stress. Emotion centred coping occurs through utilising defensive processes such as avoiding confronting the threat of the illness in a realistic way. A meta-analysis of the qualitative literature in 2006 by Steeman, Dierckx de Casterle, Godderis and Grypdonck revealed that individuals living with early stage dementia commonly experienced feelings of uncertainty and were aware of the importance of autonomy, meaningfulness and security. Steeman et al also identified the process that people with dementia go through from the recognition that something is wrong to the integration of the illness into their lives. This process reflects the struggle between self-protection and self-adjustment. Steeman et al found that the qualitative literature depicts dementia as disabling and affecting quality of life, even in its early stages.

Much research on coping styles in dementia has been undertaken by Linda Clare. Her qualitative work has focused on gaining an understanding of the ways in which people with dementia cope and adjust to their illness. In 2001 Clare identified two overarching and conflicting dimensions from her participants' accounts. The first dimension focused on maintaining continuity with the individual's prior self-concept. The second *integrative* dimension focused on a full acknowledgement of the changes experienced, their implications, and the integration of this knowledge into the individuals' self-concept. Clare stated that whilst some people with dementia displayed a mixture of the two tendencies, the majority tended more towards one dimension than the other.

Further qualitative research by Clare (2002d) identified four themes from her interviews with individuals in early stage Alzheimer's disease. She found that people tried to cope with their illness by *holding on*, *compensating*, *fighting* and *coming to terms* with it. Respondents didn't use one style of coping but utilised different strategies in different contexts and at different stages of diagnosis. The theme *holding on* encapsulated efforts to keep to a routine, use medication, hope that the diagnosis was inaccurate, hope for a cure, and trying hard to overcome the symptoms of the illness. *Compensating* for the illness included methods like relying on their spouse and avoiding situations that would be stressful. Respondents here resented their own need for assistance and recognised the danger of becoming too dependent on their partner. Both these methods of coping include the use of practical, problem solving approaches. *Fighting* Alzheimer's disease involved respondents developing a fighting spirit and finding out information about the disease, talking about it, focusing on the things that they could do well and focusing on being useful. Finally *coming to terms* with the illness led to an acceptance of the reality of dementia and an ability to balance their hope about the future with the despair of their losses. Clare viewed these coping strategies as falling along a continuum from *self protective* responses which serve to maintain a prior or existing sense of self, through to *integrative* responses which allow for the development and adjustment of the self-concept. She viewed respondents' coping strategies as reflecting the tension between the two poles of the continuum and the need to find a balance. Overall, qualitative accounts suggested a process of balancing the tension between wishing to maintain an existing or prior sense of self and the need to reappraise and reconstruct a sense of self in the light of changes in cognitive, social or environmental factors (Clare, 2002c).

Clare expanded her work on coping styles in dementia through further research. A qualitative study in 2003 led to her recognition of a spectrum of responses from *self-maintaining* to *self-adjusting*. *Self-maintaining* responses are conceptualised as minimising the difficulties, normalising, and compensating for the dementia in order to try and maintain continuity with prior sense of self. *Self-adjusting* responses are comprised of acknowledging, accepting, and fighting the illness in order to confront the difficulties and adjust sense of self accordingly.

In further work exploring changes in individual coping style over time, Clare, Roth and Pratt (2005) found that there was evidence of increased polarisation between *self-maintaining* and *self-adjusting* styles of coping in individuals with early stage Alzheimer's disease. At one year follow up there was clear continuity with the model of coping and adjustment identified in the initial interviews, though whilst initially individuals' coping responses might have incorporated aspects of both styles, there was some polarisation towards one or other of the two styles the following year. Clare et al (2005) hypothesised that this may be due to respondents' refinement in coping strategy over time or the fact that their narratives about their responses and their actual responses had unified over time.

Jacques (1988) personality types, discussed previously, can be seen to map onto Clare's (2003) dimensions of coping. Jacques' dependent personality types are similar to self-adjusting responses whilst independent types are similar to self-maintaining responses

Awareness

The concept of awareness in Alzheimer's disease has been the subject of much research and the literature supports the idea that some people with the illness demonstrate unawareness of their difficulties (Clare, Wilson, Carter, Roth, & Hodges, 2002; Clare, 2002b; Clare, 2003). Awareness involves registering the fact that changes are occurring, which in turn triggers the processes of reacting to these changes, making sense of the changes and dealing with the emotional impact of these changes. Clare (2002a, 2002b) hypothesised that the individuals' level of awareness in dementia may partly reflect a self-protective psychological response to the onset of impairment. Level of awareness is also a function of neurological based cognitive impairment and these adaptive psychological responses are constructed within a social context. Clare stated that denial in early stage Alzheimer's disease can serve an adaptive function as a coping mechanism for the sufferer, although it can cause difficulties for their family members and caregivers. Previous research has shown that individuals will selectively focus on information which confirms their existing self-perceptions and is congruent with their expectations. The effect of this is powerful and inaccurate beliefs may persist even in the face of contradictory evidence (Lepper, Ross & Lau, 1986).

Clare et al (2002) found that awareness can be linked with Clare's (2003) continuum of coping styles demonstrated by the person with dementia. They found that participants who were identified as most aware made the most *self-adjusting* responses on a Memory Awareness Rating Scale (MARS) whilst those participants identified as least aware displayed the most *self-maintaining* responses. The MARS was developed by the researchers for this study from the Rivermead Behavioural Memory Test.

Illness representations

Clare, Goater and Woods (2006) investigated illness representations in early-stage dementia. They found that most participants in their research viewed their difficulties as part of normal aging and that one third viewed their condition as stable or improving. The participants did not possess illness representations per se as the majority viewed themselves not as having an illness but instead as experiencing memory difficulties and forgetfulness resulting from aging. Gillies (2000) also found that participants in her research put their difficulties with their memory down to the perceived normality of the ageing process and consistently sought to minimise or deny the pathology of their condition. Clare et al (2006) hypothesised that this was due to lack of a diagnosis and the fact that euphemisms such as 'memory loss' were frequently used. However, even those participants who had been clearly and explicitly informed of their diagnosis remained confused over terminology and aetiology of the illness. Some participants rejected their diagnosis whilst others indicated aversion to the term *Alzheimer's*. These findings have implications for patient-professional communication and the development of interventions given that this study reveals some denial on the part of the patient to accept the reality of their condition. Clare (2003) found that where a diagnosis is actually acknowledged by the sufferer, terms such as *dementia* and *Alzheimer's disease* could be construed quite differently by different individuals. Qualitative research undertaken by Harman and Clare (2006), however, revealed that the nine respondents in their study did have a clear understanding that dementia involves a gradual and progressive decline in functioning, could not be cured, and would require adjustments in daily life in order to cope with the disease.

These studies support the hypothesis that people with dementia rely on different coping strategies at different times in their illness, and to differing degrees. This has important implications for service provision in terms of matching services and resources to the individuals' needs. In terms of early intervention, the significance of understanding individuals' own constructions of their illness and the impact that this has on their sense of self has been highlighted.

Caregiver-Patient Dyad

Thus far this review has focused on caregiver coping, the factors affecting caregiver coping, and patient coping and the factors which lead to a positive or negative outcome for patients. Much of the literature focuses on how to achieve a good outcome for caregivers *or* for patients but it is important to consider the interaction between caregivers and patients and how this impacts on outcome.

Whitlatch (2001) focused on the cyclical relationship between caregiver stress and the behaviour of the individual with dementia. She found that as the patient with dementia increased their involvement in decision making, there were marked improvements in their quality of life and a decrease in depression. Conversely, for the caregiver, quality of life decreased and there was an increase in depression. Whitlatch hypothesised that caring for a person with dementia who takes an active role in decision making could be perceived as problematic for some caregivers.

Whitlatch (2001) also identified three ways in which the caregiver-patient dyad may be incongruent in terms of what the caregiver perceives to be the preferences of the patient.

Knowledge incongruence refers to the fact that the caregiver may not know what the person with dementia prefers. For example, Whitlatch found that patients were less opposed to moving to a nursing home than their caregivers perceived. *Agreement incongruence* occurs when the caregiver may not agree with the patient's preferences, even if the caregiver thinks that they are in agreement. Whitlatch found that some of the caregivers in her study believed that their parent or spouse wanted to live in a nursing home when the patient had in fact stated that they would be ok about moving into a home but it wouldn't necessarily be their preference. Finally, *behavioural incongruence* occurs when the caregiver does not act in accordance with the wishes of the person with dementia. Whitlatch's research illustrates how caregivers' misperceptions may lead to decisions being made on behalf of the person with dementia, which however well intentioned, can limit the patient's autonomy and reduce their sense of self-worth.

McClendon, Smyth and Neundorfer (2004) found that the patients of caregivers who exhibited *wishfulness-intrapsychic* coping (wishing that things were different and that they felt differently, fantasies about how things will turn out) had increased mortality. The researchers hypothesised a number of reasons for this link between caregiver coping style and patient survival; it may reduce the amount of person-centred care the person with dementia receives resulting in an inability to maintain a personal identity, positive mental and physical attributes and a meaningful social role. Alternatively a *wishfulness-intrapsychic* coping style might be more likely to be adopted by caregivers with neurotic personality types, resulting in avoidant coping. Finally, caregivers who utilise this coping style may be more likely to relinquish in-home care and place their patient in a nursing home.

Zarit et al (2004, 2008) and Zarit et al (1980, 1986) have concluded that it is better to utilise interventions which support the caregiver rather than changing patient behaviour. He states that whilst sometimes it is possible to alter a troublesome behaviour pattern elicited by the patient, there will always be some deficits in functioning that cannot be modified through interventions. He states that taking an approach which supports the caregiver may contribute to making the situation more manageable. Given that the caregiver and patient are a dyad who react to each other, and that is often these interactions which cause stress, it is important for interventions to help caregivers address these interactions. Zarit stresses the importance of interventions which build caregivers' management skills and social resources in order to reduce burden. Interventions should aim to enable caregivers to better cope with managing patients' stressful behaviour rather than trying to address this stressful behaviour with the patient.

Issues in Caregiver Research

The issue of selection bias has been raised with regards to caregiver research. In many studies respondents have been recruited from mailing lists, support groups and service providers or are volunteers who responded to advertisements. This form of recruitment means that very little is known about the caregivers who do not use services and support groups (Barer & Johnson, 1990). Self selected opportunity samples also tend to lead to an overrepresentation of middle class non-minority respondents and it has been argued that participants who respond in this way are likely to be more resourceful and perhaps more distressed than caregivers who don't access services or respond to adverts (Mortimer, Boss, Caron, & Horbal, 1994; Zarit, 1994). Self-selection also makes is difficult for appropriate comparison groups to be selected (Mortimer et al, 1994; Zarit, 1994). It can also be argued that there is an element of information bias in the caregiver literature as the caregiver is the primary source of information. More recent studies however have started to research the experiences of the dementia sufferer (Gillies, 2000; Steeman et al, 2007; Snyder, 2001)

Methodological Considerations

In terms of evaluation studies of intervention outcomes, many studies look at the outcomes for patient or caregiver. It is important to consider combined outcomes for both members of this dyad (Schulz, 2001). In addition most research into caregivers' experience of caring for individuals with dementia has been undertaken with regards to moderate to severe dementia (Braekhus et al, 1998). Research into the experience of the person with dementia has focused more on mild dementia and Linda Clare has contributed to this body of literature. However, whilst Clare (2001, 2002, 2003) and Clare et al's (2002, 2005, 2006) studies yield interesting findings, it is important to acknowledge that this research is based on qualitative analysis of small sample sizes, although quantitative studies on caregiver stress have also been criticised for their small sample sizes (Zarit, 1994). The drawback of qualitative methodology is that it is difficult to generalise the results to a wider population but it does offer a rich and detailed account of individuals' experiences which may have been lost in larger scale quantitative analysis.

It is also important to consider the measures used in studies of caregiver burden, coping and the experience of coping. Zarit (1994) has critiqued caregiver intervention studies in terms of underestimating treatment effects. He states that measures need to be better matched to the treatments being evaluated. Most studies in the UK have utilised the General Health Questionnaire (Bruce & Paterson, 2000; Gilhooly et al, 1994) and a number of other measures have been used including the Cost of Care Index (Cairl & Kosberg, 1992), the Family Burden Interview (Bruce & Paterson, 2000), Zarit Burden Interview (Leggett et al, 2009; Schreiner, Morimoto, Arai & Zarit, 2006), Caregiver Stress Schedule (Saad et al, 1995), Relative Stress Scale (Wijeratne, 1997) and Caregivers Assessment of Management Index (Nolan et al, 2002). In terms of assessment of the experiences and awareness of dementia sufferers, a number of measures have also been used which include the Index for Managing Memory Loss (IMMEL) (Keady & Nolan, 1995b), and the Memory Awareness Rating Scale (Clare et al, 2002). This use of multiple measures makes it difficult to compare across the studies, although a number of the measures used have been found to be reliable and valid. Moniz-Cook et al (2008) state that this lack of consensus about which measures to use prevents meaningful comparisons between different studies and interventions.

Conclusions and Implications for Future Research

In conclusion, there is a substantial body of evidence which suggests that the demands of caring for a person with dementia are detrimental to the psychological and physical wellbeing of the caregiver and can have significant impact on morbidity. Models of caregiving have proposed that a number of factors can influence the level of burden experienced by the caregiver, and that these factors are influenced by both caregiver and patient variables. As the number of people living into older age is increasing it has been estimated that the incidence of dementia will increase in the population. Given that the majority of individuals with dementia are now cared for by family members rather than in institutions, we can expect to see higher levels of caregiver burden and stress. It is important that services are able to address these stressors and offer interventions, groups and resources to ease this considerable burden. Dementia itself does not present in the same way in all sufferers and this diverse symptomology results in different stresses being experienced by both caregiver and patient. In addition, the literature is beginning to reflect the experiences of dementia sufferers and the strategies and coping styles which they adopt in order to deal with the disease. Currently little is known about how these coping styles impact on the levels of burden experienced by caregivers. Increased knowledge about the stressors and the variables which influence levels of caregiver burden are vital in developing services to meet the needs of caregivers. Within the clinical field professionals have to balance both caregiver and patient needs and this interaction is often neglected in the current research. This gap in the literature needs to be addressed with further research.

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Empirical Paper

Caregivers' experience of their spouse's coping style in dementia: a study using Interpretative Phenomenological Analysis

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Running Head: The Experience of Caring for People with Dementia

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American Psychological Association publication guidelines have been applied, as if for submission to *Dementia*.

Abstract

This study uses an idiographic approach to explore and understand the interaction between eight caregivers and their spouses with dementia. Interviews were conducted with the participants recruited through a memory support group. Interpretative Phenomenological Analysis was used to create an understanding of their experience, this culminated in the development of five major themes: patient factors, caregivers' experiences, relationships, learning, and change. Overarching themes of experience, coping and change were apparent throughout the data and a number of sub-themes were also present. Insights were revealed into the interactions between the participants and their spouses, factors affecting this dyad, coping with caregiving and how they had integrated this care into their role as a spouse. This study recognises the uniqueness of the experience of caregiving and discusses the findings in relation to the existing literature, acknowledges clinical implications, and proposes possible future research.

Introduction

As the proportion of individuals in the older age range has gradually increased, so has the prevalence of dementia. It is estimated that between half a million and one million people are affected by dementia in the United Kingdom (Kitwood, 1997). Dementia is a progressive condition that affects functioning on a global level and can be expected to continue increasing in prevalence as the older population increases (Department of Health, 2001; National Institute for Health and Clinical Excellence, 2006).

As the trend moves away from institutionalised care, it is estimated that 80% of the long term non-institutionalised elderly population are cared for by their family members (Walker, 1995; Whitlatch, 2001). Caregivers can be husbands, wives or children and increasingly these family members are becoming involved in the care of their loved ones who have dementia (Zarit, Todd, & Zarit, 1986).

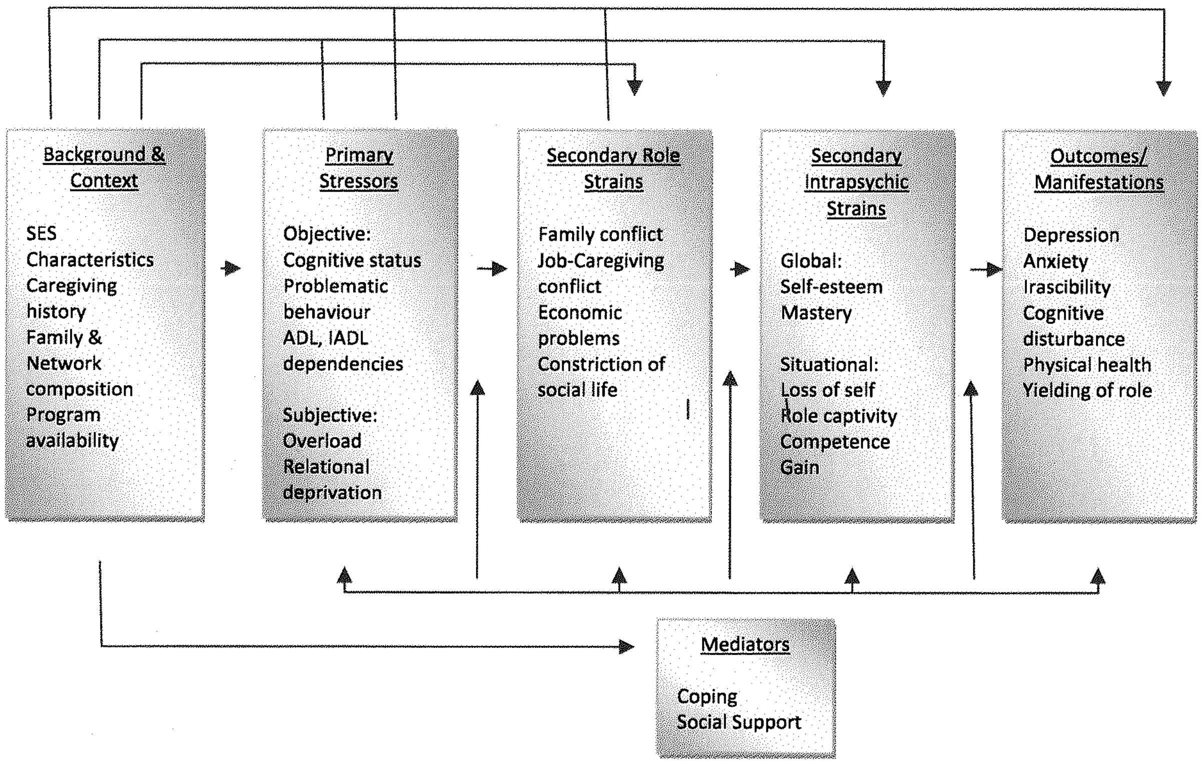
A wealth of literature has focused on the levels of anxiety and depression experienced by caregivers. Zarit (2004) found that between 40% and 70% of caregivers have clinically significant levels of depressive symptoms. A number of studies have shown that caregivers experience high levels of stress, anxiety, depression, and financial burden (Graham, Ballard & Sham, 1997; Proctor, Martin & Hewison, 2002; Schreiner, Morimoto, Arai & Zarit, 2006) and caregivers have also been found to have an elevated risk of death compared with age-and-sex-matched controls who do not provide care (Zarit, 2004).

It is interesting to consider the effect of knowledge and information about dementia on caregiver wellbeing. Graham et al (1997) conducted a study into the influence of caregiver knowledge on depression, anxiety and physical health and found that greater knowledge was associated with less depression but greater anxiety. The researchers hypothesised that these findings occurred because either increased knowledge on the subject of dementia had a causal effect on decreasing depression, or that depressed caregivers may have felt too apathetic to seek out information. Similarly, the greater levels of anxiety may have been caused by the knowledge of what is to come, or anxious individuals may have sought out more information.

Levels of caregiver burden and the ability to cope with the demands of caregiving have been found to be dependent on a number of factors. Coping patterns can be defined as "cognitive and behavioural efforts to manage external or internal demands that are appraised as taxing or exceeding the resources of a person" (Lazarus & Folkman, 1984, p. 141). Zarit et al (1986) defined caregiver burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative".

Pearlin, Mullan, Semple and Skaff (1990) examined the factors contributing to the stress process for caregivers and found that under conditions of chronic and progressive impairment, such as dementia, caregiving can expand to the point where it occupies the entirety of the relationship. They stated that there are four domains which contribute to the stress process; background and context, primary and secondary stressors, mediators of stress, and manifestations of stress. Their model was proposed with Alzheimer's caregivers' stress in mind but is also relevant to other forms of dementia as it emphasises the subjective components of relationships which attribute to caregiver burden. See figure 3.

Figure 3: A conceptual model of Alzheimer's caregivers' stress (Pearlin et al, 1990)



The coping style of the person with dementia may also be an important factor affecting the level of stress experienced by the caregiver. Research by Whitlatch (2001) and Kitwood (1997) has shown that when individuals with dementia take an active role in their care, this is problematic for some caregivers. Specifically however, research has found that for the person with dementia, involvement in decision making leads to a self-reported increase in quality of life and decrease in depression. Conversely this coping style led to caregivers reporting increased depression and decreased quality of life (Whitlatch, 2001). It is hypothesised that having complete control over care decisions may be less stressful for the caregiver than having to discuss less desirable options with the individual with dementia.

The level of awareness of individuals with dementia has been considered to be a symptom of the disease; the progression of the disease leads to a lack of awareness much as it affects cognitive and other aspects of functioning (Green, Goldstein, Sirockman & Green, 1993). However, recognition of awareness can also be viewed as a coping style of people with dementia (Keady and Nolan, 1995a, 1995b). Recently the psychological and social context has been proposed to affect levels of awareness and that whilst in some contexts people seem unaware of their diagnosis, they present as acutely aware in others (Clare, 2003). Clare (2003) hypothesises that whilst some individuals cope by confronting difficulties in a head on fashion, others attempt to minimise threats experienced by denying difficulties. Clare (2003, 2009) has proposed a model based on a phenomenological study into people with early stage Alzheimer's disease. She conceptualises coping responses as falling along a continuum from self-maintaining (preserving pre-existing self-concept) to self-adjusting (integrating new experiences and adapting self-concept). Clare, Wilson, Carter, Roth and Hodges (2002) found that self-adjusting styles significantly correlated with higher levels of awareness, and self-maintaining styles with lower levels of awareness. Clare (2003) rated individual accounts on a nine-point scale which reflects the continuum of coping responses. She stated that lack of awareness, or denial, is a coping strategy utilised by people with dementia which has an adaptive function. However, this denial can cause problems for caregivers and family members as individuals will selectively focus on information which confirms their self-perceptions (Clare, 2002). Research by Keady and Nolan (1995a) has hinted at the importance of the caregiver – patient dyad in that the period whereby disclosure and mutual recognition that something is wrong can be highly influential in shaping future coping patterns.

In terms of individual differences in dementia, Jacques (1988) proposed six main personality types seen in dementia based on his clinical work. These types included 'dependent' personality types who accept help readily but are sometimes reluctant to stand on their own feet and take the initiative, and 'independent' personality types who may be resistant to facing the truth about their illness and its consequences and like to feel in control of situations. These personality types can be seen to map onto Clare's (2003) dimensions of coping. Dependent personality types are similar to self-adjusting responses whilst independent types are similar to self-maintaining responses. Kitwood (1997) states that only a small minority of people are able to face the onset of dementia without high defences and drew parallels between Jacques personality types and Buckland's (1995; cited in Kitwood, 1997) six main personality clusters. Kitwood views Buckland's anxious-passive type as resembling Jacques dependent type.

There is considerable evidence in the literature to suggest that caring for an individual with dementia is highly stressful and can impact on the psychological and physical wellbeing of the caregiver and have a significant impact on mortality. Dementia itself has a diverse symptomology and can therefore present differently in different individuals resulting in differing levels of stress being experienced by sufferers and caregivers. Interventions aimed at caregivers for people with dementia need to consider a number of factors in order to help reduce caregiver burden. Studies into caregiver burden inform the design of interventions and Chappell (1996) stated that "it is axiomatic that we cannot support people appropriately if we do not fully understand their needs". Nolan et al (2002) have stated that the aim of interventions for caregivers should be to enhance the quality and meaning of life for both patient and caregiver and to promote satisfaction and expertise within the caring role.

Qualitative research has started to investigate the experiences of people with dementia and has begun to identify the coping styles they adopt in order to manage their illness. For example, Clare (2002) acknowledges that only a small number of studies have focused on coping in the early to middle stages of dementia. However there is still very little in the literature on how the models of coping utilised by the person with dementia impact on the level of stress experienced by the caregiver. Increased knowledge about the stressors and the variables which influence levels of caregiver burden are vital in developing services to meet the needs of caregivers. The current study aims to address this gap in the research literature and aims to explore and understand in more detail the experiences and needs of caregivers and their perception of the coping style shown by their spouse with dementia. Using Interpretative Phenomenological Analysis, this research aims to give a useful, thorough and quality first-person account of the subjective experience of eight caregivers of spouses with dementia.

Method

Design

A qualitative design was chosen for this research. It was decided that this method was the most appropriate given that this study would be explorative in nature and aimed to explore in detail the experiences of caregivers. A qualitative approach offers a rich and detailed understanding of an individual's experience and is concerned with meaning in context (Willig, 2008). Qualitative methods have been widely utilised in research with individuals with dementia and their caregivers (Clare, 2001; 2002; 2003; Clare, Goater & Woods, 2006; Clare, Roth & Pratt, 2005; Gillies, 2000; Preston, Marshall & Bucks, 2006; Steeman, Dierckx de Casterle, Godderis & Grypdonck, 2006). This precedent strengthens its applicability for use in the current study.

Interpretative Phenomenological Analysis (IPA) was selected as an appropriate form of analysis as it aims to explore the meanings that participants assign to their experiences and regards them as experts with regards to their own experiences. IPA provides opportunities for participants to tell their own stories, in their own words, in detail, and is concerned with exploring experience in its own terms (Smith, 2004; Smith, Flowers & Larkin, 2009). IPA uses an established, systematic, rigorous and phenomenologically focused approach to the interpretation of first-person accounts. It is a meaning focused method which is committed to understanding the first-person perspective from the third-person position through intersubjective inquiry and analysis (Smith et al, 2009). IPA looks at the whole person in the context of their relationships and environment and offers an empathic approach to understanding experience (Smith, 2008). IPA is widely used throughout a range of disciplines within psychology, particularly within the fields of health and social psychology (Smith et al, 2009). IPA has also been used in a number of studies exploring the experience of dementia (Clare, 2001; 2002; 2003; Clare et al, 2005; Clare et al, 2006; Preston et al, 2006). Alternative qualitative approaches were considered in addition to IPA. However IPA was considered most appropriate given the aims and scope of the study. Thematic analysis, grounded theory, discourse analysis, and narrative theory were considered but were decided to be less appropriate for this study than IPA as this research aimed to focus attention on the lived experience of the participants in detail. For a detailed rationale of the use of a qualitative methodology and IPA please see Appendix A.

Whilst the design of the current study is predominantly qualitative, some quantitative data was also collected via questionnaires in order to supplement the qualitative data. The quantitative measures used are discussed in detail in the 'Materials' section of this study.

Participants

Sample size and criteria

The sample of participants interviewed in this study were eight caregivers whose spouses had a diagnosis of Alzheimer's disease or vascular dementia. In terms of sample size, Smith (2004) advocates a small sample size for use with IPA. Between six and eight participants are recommended as an appropriate number as this enables the researcher to hold all cases in mind and make meaningful connections within the data (Smith and Eatough, 2007). In keeping with these recommendations, the current study used a sample size of eight participants.

This study was concerned with the experiences of caregivers who care for a spouse with a diagnosis of mild dementia only. A diagnosis of mild dementia was chosen because the study aimed to investigate what is is like to care for a spouse with a particular coping style and it was thought that this would be more evident in mild dementia. As dementia progresses, sufferers exhibit higher levels of behavioural disturbances and caring tends to revolve around these needs (Gilhooly, Sweeting, Whittick & McKee, 1994). Previous research by Linda Clare (2001; 2002; 2003; Clare et al, 2005; Clare et al, 2006) which most closely resembles the current study has included participants with mild dementia (MMSE scores of 18 and over) so it was decided to follow this precedent.

Exclusion criteria included caregivers of individuals with Lewy Body dementia or frontal dementia as were caregivers and dementia sufferers aged less than 60 years old. The criteria were chosen as these dementias present slightly differently presenting different challenges to caregivers. In addition younger caregivers and dementia sufferers were anticipated to be dealing with different challenges such as possibly trying to work full time or caring for grown-up children still living at home. Caregivers of people with co-existing mental health disorders were also excluded as this would complicate the demands on the caregiver. The main caregiver in this study was spouse of the person with dementia and thus caregivers with other relationships to the person with dementia were excluded. Finally caregivers of individuals with a Mini Mental State Exam (MMSE) score of below 18 were excluded.

Sample demographics

The sample of caregivers interviewed has ages ranging from 63 to 77 (mean age of 71.4) and was comprised of seven females and one male. Their spouses had ages ranging from 69 to 81 (mean age of 74.2), lived at home and had dementia. All participants were of white British ethnic origin. The MMSE scores of the participants' spouses ranged from 18 to 26. Details of participant demographics can be seen in table 1. All participants have been given a pseudonym unrelated to their real name to protect their confidentiality.

Table 1: Participant demographics.

Name of Caregiver	**Age**	**Name of spouse**	**Age**	**Diagnosis**
Beryl	77	Edward	81	Alzheimer's disease
Ted	76	Maureen	75	Alzheimer's disease
Sheila	68	Paul	73	Vascular dementia
Sue	70	John	69	Alzheimer's disease
Iris	63	Tom	73	Alzheimer's disease
Joan	76	Rod	75	Vascular dementia
Beth	72	Terry	74	Vascular dementia
Ann	69	Bob	74	Alzheimer's disease

Recruitment

The study was conducted with support from a local Older People's Community Mental Health Team (OPCMHT). The researcher attended a memory support group which was run by volunteers and supported by the OPCMHT. Both caregivers and people with dementia attended the support group following inclusion in the Memory Matters courses (for people in the early stages of dementia and their caregivers) run by the OPCMHT. The researcher presented her research ideas to the memory support group and circulated letters of invitation to potential participants (see Appendix B). A member of staff from the OPCMHT who regularly attended the memory support group helped identify potential participants whom the researcher then approached.

The researcher also attended a staff meeting at the OPCMHT and presented her research ideas to the team and circulated letters of invitation. The idea being members of the team would act as gatekeepers passing on the details of potential participants who agreed to meet the researcher. However, no participants were recruited in this way.

Materials

Following a semi-structured interview, the participants were presented with two questionnaires, The Zarit Burden Interview (ZBI) and the Depression Anxiety Stress Scales (DASS). The ZBI presents caregivers with a series of 22 questions regarding perceived strain. Example questions on the ZBI include: 'Do you feel you should be doing more for your relative?', 'Do you wish you could just leave the care of your relative to someone else?'. The degree to which caregivers endorse each item is rated along 5-point Likert-type scales ranging from never to nearly always. Reported reliability coefficients for the full 22-item scale range from 0.83 (Majerovitz, 1995) to 0.94 (O'Rourke & Wenaus, 1998).

The DASS is a set of three self-report scales designed to measure the states of depression, anxiety and stress. Each of the three DASS scales contains 14 items, divided into subscales of 2-5 items with similar content. Subjects are asked to use 4-point severity/frequency scales to rate the extent to which they have experienced each state over the past week. Scores for Depression, Anxiety and Stress are calculated by summing the scores for the relevant items (Lovibond and Lovibond, 1995). Whilst the DASS is an Australian scale, it has been found to be a reliable and valid measure of the constructs it was intended to assess and it's applicability in the UK has been enhanced by the provision of a large sample of normative data (Crawford and Henry, 2003).

Procedure

All eight participants were interviewed within their own home. Prior to the interview, the researcher spent time introducing herself and building rapport with the participants. An information sheet (See Appendix C) was presented to the participants and they were asked to sign a consent form (See Appendix D). Following verbal and written consent being obtained, the researcher began recording the interview. Following the interview a debriefing statement (See Appendix E) was given to participants which was accompanied by a verbal debriefing and a verbal invitation to receive written feedback once the study was completed. Interviews lasted between 30 minutes and one hour.

Two of the participants chose to be interviewed with their spouse present. The participants were encouraged to provide their account without input from their spouse. Any input from the spouse was excluded from the analysis.

Semi-structured interview

The use of semi-structured interviews is recommended when using IPA as a method of analysis (Smith et al, 2009). A semi-structured interview facilitates a comfortable interaction with the participant which will enable them to provide a detailed account of the experience under investigation (Smith et al, 2009). An interview schedule (See Appendix F) was designed to include open and expansive questions in order to encourage the participants to talk at length. The interview schedule consisted of ten questions based on recommendations made by Smith, Flowers and Larkin (2009) who suggest that between six and ten open questions will tend to occupy between 45 and 90 minutes of conversation. The interview schedule was piloted with a caregiver whose wife had suffered a stroke and experienced some difficulties with her memory and cognitive functioning. Following this pilot interview the purpose of the study was discussed with the caregiver and it was agreed that the questions were appropriate for eliciting the information required. Therefore no changes were made to the interview schedule. The interview was piloted only once due to the lack of availability of participants and the researcher acknowledges that it may have been beneficial to have repeated the pilot to improve reliability. Additionally the researcher acknowledges that operationalising the meaning of coping during the interviews may have been useful. The interviews with participants were informal and flexible; they took the form of a conversation. The interview schedule was designed as a guide to prompt questioning rather than for use as a restrictive questioning schedule. The researcher utilised clinical interviewing skills such as reflection, active listening and open ended questions to facilitate discussion and allow interviewees to tell their story in their own way. The researcher tried to use the terminology used by the participants during interviews; for example 'memory problems', 'difficulties', 'illness'.

Ethical Considerations

Ethical approval was sought and obtained by the University of Southampton ethics committee (See Appendix G) and the local NHS Research Ethics Committee (See Appendix H). In addition site specific approval was sought and obtained from the NHS Research and

Development Office (See Appendix I). These processes involved risk assessment which included consideration of visiting participants in their own homes. Informed consent was a key consideration throughout this study. Participants were asked to give formal written consent prior to the interviews and were reminded during the interview process that their ongoing participation was voluntary. The information sheet was reviewed prior to each interview which reminded the participant that they may withdraw their participation at any time and that all material relating to the interview was anonymous and would be stored securely.

The topics covered in the current study meant that there was a degree of emotional risk on behalf of the participants. The subject matter relating to their experiences, their loved ones, and their coping is sensitive and emotional and the possibility of participant distress was considered throughout this research. Following the interview the researcher asked if the process had raised any concerns or worries for the participants. During the planning stage of the research, it had been proposed that if participants did experience distress then this would be reported to their care-coordinator at their local OPMH community team. However, participants did not report feeling concerned about the emotional impact of the interviews. This fits with Zarit's (2008) observation that "most caregivers will want to talk about their own situation".

Data Management

The interviews were transcribed and anonymised so that they did not contain any identifying features. The process of transcription was undertaken in accordance with guidelines so that pauses in conversation, overlapping speech, and interruptions are recorded in the transcription (Smith et al, 2009). The participants' names were changed in the transcription in order to maintain their confidentiality and anonymity. Following transcription the audio recordings of the interviews were destroyed. Descriptive statistics will be used to summarise the quantitative data gathered from the ZBI and the DASS.

Analysis

The analysis of transcripts was conducted in accordance with guidelines provided by Smith et al (2009). They state that there is no right or wrong way to conduct IPA analysis and IPA researchers are encouraged to be innovative in how they approach the data. However Smith et al (2009) do provide a heuristic framework in order to guide analysis. IPA necessitates that the researcher engages in a process of interpretation through sustained engagement with the text. Smith et al (2009) emphasise that the analysis is a joint product of both participant and researcher. The primary concern of IPA is the lived experience of the participant and the meaning that they make of this experience; however, understanding of the first-person perspective is arrived at from the third-person position therefore IPA analysis is subjective. The subjectivity is dialogical, systematic and rigorous in its application and the results of this are transparent to the reader (Smith et al, 2009).

In order to consolidate an appropriate understanding of the IPA process, the researcher attended an IPA workshop prior to commencing the current research (See Appendix J). This workshop provided a practical and theoretical grounding in the research process and enabled the researcher to undertake her research with more confidence and knowledge. Researchers experienced in IPA were also consulted during the research process. A reflexive diary was kept by the researcher throughout the research process. IPA recognises that research is a dynamic process and the researcher needs to be aware of the concepts, values and preconceptions that they bring to the process of analysis. The reflexive diary was used for this purpose (See Appendix K for a reflexive account of the researcher's perspective).

Analysis of the transcripts was undertaken in accordance with Smith et al's (2009) guidelines. Initially transcripts were read and re-read and notes were made in the left hand margin if the material was significant or interesting. The process of engaging with the text and re-reading was important allowing the researcher to become familiar with the text. Re-reading and reviewing the text allows new and important insights to be noted each time and ensured that the themes did represent what the participants had said during their interviews (Smith et al, 2009). This process is known as phenomenological or descriptive coding. Following this process, the researcher began the interpretative coding process. The researcher returned to the text and documented emerging themes in the right hand margin. Interpretative coding captures a higher level of abstraction, interpretation and use of psychological terminology. The themes were noted and this process was completed for each transcript. The themes were then reviewed and the researcher looked for connections between them. Clusters of themes were identified and themes were organised into a structure which reflected the most interesting and important aspects of the participants' accounts. Themes were named using participants own words. The themes that the researcher chose as the focus of the study resulted in a coherent, comprehensive account of the experience of caring for a spouse with dementia and the way in which their spouse coped with their illness. It must be remembered that whilst IPA can be characterised by a set of common processes (moving from descriptive to interpretative, from the particular to the shared) and principles (focus on personal meaning making and understanding of the participants' point of view) these are applied flexibly and there is considerable room for manoeuvre (Smith et al, 2009).

Validity

Validity can be seen as a problematic concept for qualitative researchers (Willig, 2008) and Yardley has presented four broad open ended principles for assessing the quality of qualitative research. IPA is able to address these principles and demonstrates good validity (Smith et al, 2009; Yardley, 2000). Yardley's (2000) principles were designed to be used flexibly as a guideline (See Appendix L for a more detailed account of these principles):

- Sensitivity to context – research should be sensitive to the existing literature in the area. *The current study aimed to explore a gap in the existing literature. IPA has also been used in the area as a means of exploring the experiences of individuals with dementia and their caregivers (Clare 2001; 2002; 2003; Clare et al, 2005; Clare et al, 2006; Preston et al, 2006)*
- Commitment and rigour – research should show competence and skill in the methodology used, and completeness in terms of data collection, interpretation and analysis. *The researcher attended formal training in the methodology used and adhered to the principles outlined by Smith et al (2009).*
- Transparency and coherence –research stages should be clearly described in the study and should be replicable. *The current research was transparent; it followed prescribed stages (Smith et al, 2009) and the analysis was reviewed by two supervisors to ensure transparency.*

- Impact and importance – research should tell the reader something interesting and important and have clinical utility. *The current study explores an important and interesting area and usefully contributes to the literature.*

These broad principles were considered throughout the planning, research, analysis and interpretation stages of the study. The current study was grounded in and informed by the available literature, it showed fidelity to the IPA model through training in IPA methods and consultation with experienced IPA researchers, it was transparent in terms of data collection and analysis. The experiences of caregivers and the stresses they experience help inform the interventions, services and resources available to caregivers making it relevant to the clinical field.

Reliability

Reliability refers to whether a measurement yields the same answer on different occasions. Qualitative research is less concerned with reliability as it aims to explore the particular, possibly unique, phenomenon in great detail (Willig, 2008). In addition, IPA acknowledges that the researcher does not access experience directly from the participants' accounts, but through a process of inter-subjective meaning making. The accounts produced by the researcher are the product of a brief relationship with participants and take the form of third-person interpretation of participants' first-person reflections. The accounts reveal something about a particular person's relationship to a given phenomenon, in a given context, and accessed at a given point in time (Smith et al, 2009). However it is important to ensure that the results are a reliable interpretation of the unique accounts. In order to ensure transparency the researcher disseminated her transcripts, with phenomenological and interpretative coding, to two supervisors. The supervisors were then able to see how the researcher had formed her interpretations based on the transcripts. Whilst IPA recognises that different researchers may identify different themes, it is nevertheless imperative that the process is transparent.

Results

Quantitative Data

Following the interviews, caregivers were given two questionnaires to complete, the ZBI and the DASS. The results of the ZBI can be seen in table 2.

Table 2: Descriptive Data for Zarit Burden Interview (ZBI)

Caregiver	ZBI Score	Qualitative Description
Beryl	30	Mild to Moderate
Ted	42	Moderate to Severe
Sheila	38	Mild to Moderate
Sue	66	Severe
Iris	30	Mild to Moderate
Joan	46	Moderate to Severe
Beth	28	Mild to Moderate
Ann	46	Moderate to Severe

These results show that all the caregivers experienced some level of burden with regards to caring for their spouse. Interestingly some of the results from the ZBI conflict with the caregivers' own appraisal of the level of burden they experience. For example, Ted's scores reveal that he experiences mild to moderate burden and was only two points away from a score of severe burden (≥40). However during the interview he described his experience in a way that sounded less burdensome: "the thing is the whole job if you like is not that onerous, it's just restrictive" (Ted, p3. 138-139).

The results of the DASS questionnaires, which can be seen in table 3, revealed a similar pattern. The researcher was surprised to see that the caregivers whom she had perceived as most stressed, anxious or depressed following the interviews did not necessarily have the highest scores on the DASS. For example, Beth presented as tearful with symptoms of depression during the interview but scored in the normal range on the depression section of the DASS. Similarly Ann presented as tearful and low during the interview but scored within the normal range on this section of the DASS. However Joan presented as struggling to cope emotionally during the interview and this was reflected in her scores across all sections of the DASS.

Table 3: Descriptive Data for Depression, Anxiety and Stress Scales (DASS)

Caregiver	DASS Score: Stress	Qualitative Description: Stress	DASS Score: Anxiety	Qualitative Description: Anxiety	DASS Score: Depression	Qualitative Description: Depression
Beryl	12	Normal	1	Normal	12	Mild
Ted	15	Mild	10	Moderate	10	Mild
Sheila	12	Normal	3	Normal	14	Moderate
Sue	11	Normal	6	Normal	1	Normal
Iris	2	Normal	1	Normal	0	Normal
Joan	34	Extremely Severe	23	Extremely Severe	21	Severe
Beth	12	Normal	11	Moderate	2	Normal
Ann	8	Normal	2	Normal	8	Normal

Qualitative Data

Participants' accounts were rich and detailed providing a wealth of data about what it is like to be a caregiver for a spouse with Alzheimer's disease or vascular dementia. The participants coherently described their experiences of caring for a loved one and showed insight into the losses and challenges this entailed, both for them and their spouse. Participants talked about the impact of caring on their everyday lives, their relationships, their emotions, how they coped with the challenges they faced, their fears for the future and the losses that they had experienced.

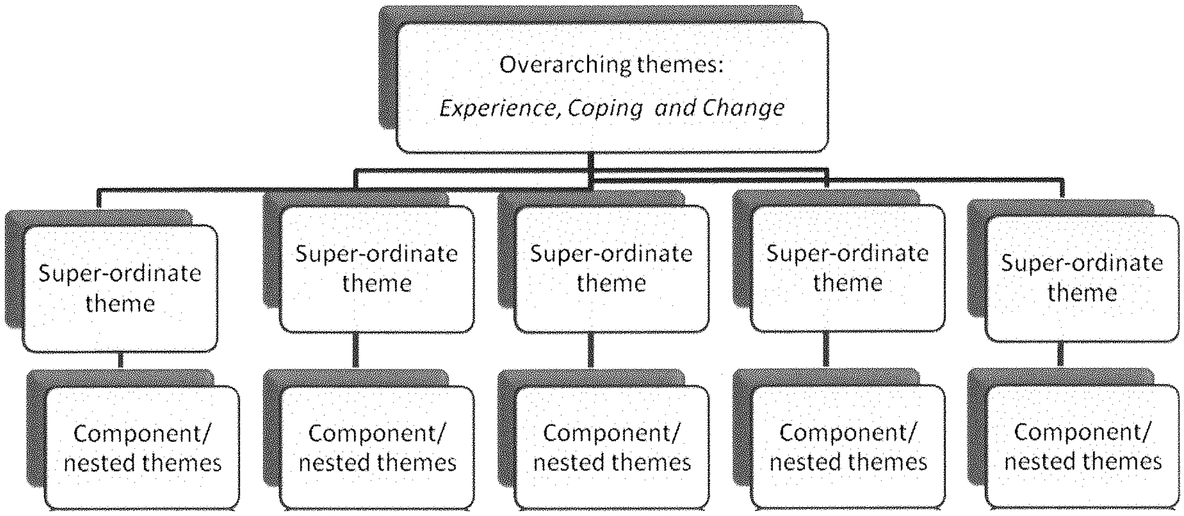
The researcher had hoped that the interviews would provide insight into how the caregivers experienced the coping style of their spouses and how this then impacted on how they coped in line with the aims of the study. The participants did talk about how they believed their spouses coped with their illness but not in sufficient depth for the researcher to be able to map these styles onto Linda Clare's (2003) and Clare et al's (2005) spectrum of responses from *self-maintaining* to *self-adjusting.* In addition there were not significant differences between the coping styles described by the participants.

Overall the participants' accounts were about how they coped with caring for their spouse and how they had integrated this care into their role as a husband or wife. Some coping themes which emerged included adapting, learning and adjusting their way of life as a means of coping whilst coming to terms with their losses and the unpredictability of the future. The themes outlined in Table 4 are those that the researcher thought best encapsulated the accounts presented by the participants.

Description of Themes

The process of analysis resulted in the development of five super-ordinate themes. These themes comprise *patient factors, caregivers' experiences, relationships, learning, and changes*. Each super-ordinate theme consists of a set of nested themes as outlined in table 4 and a framework of the themes can be seen in Figure 2. These themes all reflect experiences of interactions between caregivers and their spouses and give an understanding of this dyad. Participants' own words have been used to name these nested themes in order to encapsulate the meaning of these sub-components. Analysis of the participants' accounts revealed the individual's unique experiences. Evidence from participants' accounts will be provided for each theme.

Figure 4: Diagram illustrating the framework of themes



The five super-ordinate themes are situated within an overarching framework of *experience, coping* and *change*. These overarching themes permeate all the super-ordinate themes and nested/component themes. The overarching theme of *experience* provides an understanding of what it is like to be the caregiver of a spouse with dementia and gave the researcher an understanding of how being a caregiver is experienced by the participants in the study. From a psychosocial standpoint this overarching theme reflects how the participants' psychological and emotional experience is affected by being a caregiver for a spouse with dementia. *Coping* reflects the emotional, behavioural and cognitive strategies that the participants utilise in order to cope with the *experience* of being a caregiver. *Change* emerged as the process through which the participants cope with their experience. These overarching themes contributed to the researcher's understanding of how the caregivers in this study coped with the caregiving role.

Table 4: Overview of Themes

Super-ordinate Theme	**Component Themes**
1) Patient Factors	▪ 'I can see the hurt in his eyes' ▪ 'Me and my shadow' ▪ 'He still wants to do things' ▪ 'Not wanting to admit' ▪ 'He tells everybody that I'm a good nurse'
2) Caregivers' Experiences	▪ 'Just below the surface all the time' ▪ 'We're soldiering on' ▪ 'It can be the loneliest place in the world' ▪ 'It's because he's finding it hard that I'm finding it hard'
3) Relationships	▪ 'You're a caregiver just by being a wife' ▪ 'I'll have to go and get two single beds' ▪ 'What you miss' ▪ 'It makes it more difficult for me'
4) Learning	▪ 'Shoulds' ▪ 'I've worked out a system now' ▪ 'I take each day as it comes'
5) Changes	▪ 'Now it's down to me' ▪ 'He was interested in cooking' ▪ 'It's gradually increased' ▪ 'Good days and bad days'

Many of the super-ordinate themes and component themes overlap and are interconnected, as has been highlighted in other studies utilising IPA. Whilst this will be discussed further in relation to each theme, it is important to recognise that the quotes used to illustrate particular themes may also relate to and support other themes. The quotes used were chosen by the researcher to best reflect the theme under discussion.

1) Patient Factors

This theme represents the numerous different issues raised by caregivers about their spouse in relation to their dementia. The researcher felt that the sub-themes worked together to form a super-ordinate theme regarding how the caregivers' defined how their spouses coped with and experienced their illness. This super-ordinate theme focuses on how the caregivers see their spouses' reactions to their illness and how they cope with being cared for. There are both commonalities and contrasts reflected in the component themes.

'I can see the hurt in his eyes'

Discussion relating to the impact of dementia on their spouses raised the issue of how the caregivers felt that their spouses had reacted emotionally to their diagnosis. Additionally they perceived that dementia itself had caused an emotional change in the individual. Analysis of the transcripts revealed that frustration was a common emotion experienced by the individuals with dementia and that the caregivers understood why their spouse was frustrated. The caregivers interviewed showed patience in their reactions to this frustration which was often vented towards them. Caregivers would contrast their spouses' emotional state prior to their diagnosis with their current presentation. The following excerpts illustrate this emotional impact.

"He gets frustrated which is understandable and cross with himself because he can't control it"

(Beryl, p4. 197-198)

"When he's frustrated you know if I've said something it was oh f##k off whatever off to me and that's not his normal but he does if I've sort of said something"

(Iris, p2. 68-70)

"I think he's getting depressed I think he's got very frustrated, he was always very even"

(Ann, p3. 107-109)

Beth's experience of the emotional impact of dementia on her husband was that he struggled to control his emotions as they there were constantly near the surface. Music appeared to bring these emotions out. Beth was also aware that this level of emotional lability embarrassed her husband.

"He's very emotional now music as soon as music you see he's in tears and um not before this dementia"

(Beth, p5. 212-214)

'Me and my shadow'

All the caregivers interviewed talked about how their spouses were dependent and reliant on them, sometimes possessive. Some participants seemed more accepting of this whilst others described it as restrictive. Participants discussed how they tried to engage their spouses in tasks in order to reduce this dependence, encouraging them to do as much as possible for themselves. One of the issues raised by the caregivers was that the caring role was like parenting in this regard.

"the thing is I call it me and my shadow because from the moment, right he's quite happy to take the dog for a walk but going anywhere he's beside me like a shadow, you know going shopping or, or doing anything. If I've got to go to the surgery or to the hospital he's always you know with me'

(Beryl, p2. 97-101)

"I've worked out a system now, if I'm around he will ask me to do things I can't do my shoes, I can't do my socks so what I tend to do is to come down the stairs making sure that he's safe"

(Sue, p2. 66-68)

"you've to be on the button all the time really haven't you it's like when you have a young child a two year old [laughs]"

(Joan, p2. 63-65)

'He still wants to do things'

This sub-theme is similar to the last in terms of reduction of dependence. The individuals were perceived by their caregivers as compensating for the things they could no longer do by contributing in other ways. They didn't want to be defined by their illness.

"he's always saying "what can I do to help you, what can I do to help you?" until I could go mad but that's why I try and find something constructive for him to do all the time like walking the dog"

(Beryl, p.4, 185-188)

"he'd cook the meal but he couldn't do that now and um so I do all the cooking but he's very helpful you know he always says I'll wash up and he always washes up"

(Beth, p3. 145-148)

"He still tries to do stuff and we do crosswords he does crosswords and he gets me to the bits he can't do and he really tries"

(Ann, p5, 239-240)

Shelia's husband, Paul, wanted to maintain his independence and control by having the choice to drive or not instead of having this choice taken away from him.

"he doesn't want to drive but he doesn't want to give his license up so we got another form through this year to fill out again"

(Sheila, p5. 246-248)

'Not wanting to admit'

The issue of acceptance with regards to the diagnosis of dementia resulted in some contrasting strategies displayed by the individuals with dementia. Some participants said that their spouse was accepting of the diagnosis, tried to cope as best they could with this knowledge and compensated for the difficulties caused by the dementia. Others, however, painted a very different picture of their spouse who did not accept their diagnosis and was fighting against it. Analysis of the transcripts suggested that this cognitive strategy employed by some patients was not helpful for the caregivers.

"he's philosophical about it I suppose is the word, it's one of those things .... and there's nothing he said we can do about it except keep motivated"

(Beryl, p4, 182-184)

"[gestures to the walking poles on the other side of the room] he's got two of them, she bought them for him, he said I'm not using them"

(Sheila, p4. 187-188)

"he hasn't accepted the fact that he's, I don't think he's accepted it very well, that he has got dementia, he's still trying to claw back things"

(Joan, p1, 22-24)

'He tells everybody that I'm a good nurse'

Interviews raised the issue of whether the caregivers felt that their spouses had insight into the work that comprises the caring role and whether the caregivers felt this care was appreciated. These attitudes contributed to how the caregivers experienced their role and possibly the levels of stress experienced.

"I do point out to her that I've only got her best interests at heart and end up with the result does get very (laughs). I think she is wilful at times ..."

(Ted, p4, 171-175)

"(Interviewer asks: do you think he has any idea of how stressed you are at all?) No, I don't think so, not truthfully"

(Sheila, p5, 227-228)

"Um reluctantly accepting my help I think, he is very resentful you can tell that, very resentful um but the alternative is for a perfect stranger to look after him"

(Joan, p5, 204-206)

"I do get upset but he never actually says he's sorry really now you know even if he's he just accepts that I've got to accept his bad behaviour which perhaps I do"

(Ann, p.7, 353-355)

2) Caregivers' Experiences

All the participants talked about the emotional impact of being a caregiver. Some participants presented as emotional and tearful during the interviews and it was clear that being a caregiver for a spouse is an emotional and difficult role. Some participants presented as more fragile than others but they were all striving to present themselves as coping and strong to the outside world and not admitting their vulnerabilities to others. Their understanding of what their loved one was experiencing appeared to mediate their emotional coping.

'It can be the loneliest place in the world'

Participants talked openly about the strains of caregiving and the impact that this had on their emotional coping. The theme of loneliness and isolation was reflected by some participants and overall the interviews suggested an initial lack of knowing how to cope with being a caregiver. Participants had adapted to the emotional demands of their role over time. These ideas are also discussed in the super-ordinate theme of *Learning.* Many of the participants stated that their emotional coping had been more of a struggle in the earlier stages of diagnosis.

"I used to get really really quite anxious and I think this is why you build up and build up and this is when I used to get this depression um because I was just anxious about him being on his own, I recognised that I couldn't think properly I couldn't assemble my thoughts"

(Sue, p3. 115-119)

"I didn't feel right I couldn't see into the future, I couldn't think that there was anything good happening in the future" (Sue, p3. 122-125) "this counselling I'm going to have might help me to cope with it a bit better because sometimes I break my heart"

(Joan, p5. 214-215)

"I was a bit weepy and I think they detected that I was a bit low and needed a bit more help but um my outward sign is that I'm fine"

(Joan, p6. 295-297)

'We're soldiering on'

The language used by participants when talking about the caregiving role was of interest to the researcher. Many participants remarked on the fact that caring is a 24 hour role and used words such as 'work' and 'battle' to describe caring for their spouse. This language gave an indication of the hard work and the onerous aspect of caregiving which participants sometimes seemed uncomfortable stating explicitly when talking about their spouse.

"the thing is the whole job if you like is not that onerous, it's just restrictive, it only becomes onerous when you want to do something and you can't, you can't do it"

(Ted, p3. 138-141)

"I might say but I could get them washed and dried by tomorrow for you rather than have the battle about it which we've had in the past with clothes and baths"

(Iris, p1. 36-39)

"it isn't an easy job but it's one I've elected that I'm going to do"

(Joan, p5. 232-233)

'Just below the surface all the time'

During the interviews the researcher sensed that some of the participants were only just coping with the role of being a caregiver. They presented as fragile and struggling to cope. Some participants were taking anti-depressant medication and one was about to pursue counselling. Whilst the overall image participants wanted to portray was one of being able to cope, it became apparent that this was not always the case.

"The constant.... I suppose really [gets tearful] apart from when he does his nut yeah it just doesn't cease"

(Sheila, p4. 197-198)

"some days it does it does, it's overwhelming some days I feel I want to shut the door and run really, truthfully"

(Iris, p3. 122-123)

"I personally sometimes feel I want to throw the flannel in you know if I could put on my hat and coat and walk out sometimes I would but I can't"

(Joan, p5. 208-210)

'It's because he's finding it hard that I'm finding it hard'

Interviews revealed that the role of a caregiver is demanding on many levels from constant vigilance and physical demands to the lack of time to oneself. It indicated not only a change in role for the caregiver but also coming to terms with progressive illness and grieving for someone they love. The caregivers' empathy exacerbated this strain because they felt deeply and understood their partners' losses.

"knowing full well that one used to do quite a lot, was very active in lots of things and now isn't must be terrible must be awful for him" (Iris, p2. 78-80) "it becomes out of all proportion seemingly to me but it's important to him he wants it done and out of the way off his mind I suppose"

(Sue, p1. 23-25)

"I said to Terry I know you can't remember I do understand and he'll just keep saying but I'm sorry I can't remember I can't help it he's always saying I can't help it I say Terry I know you can't help it"

(Beth, p7. 322-325)

3) Relationships

This theme represents the different issues raised by participants concerning their relationship with their spouse. Participants talked about how their relationships had been affected by dementia and the impact this had on their identity and sense of self. This was a common theme raised by participants, the shift in the dynamics of their relationships produced great sadness and loss.

You're a caregiver just by being a wife'

It was of interest to the researcher how the caregivers viewed their role. The sub-theme *'we're soldiering on'* reflected that being a caregiver is like a job, it is work. However for some participants it was hard for them to define a change in their role because they perceived being married as caring for their loved one. The current caregiving role was perceived as a natural extension of years of caring for their spouse. These ideas highlight a level of conflict in some of the participants' perceptions of their role; they stated that they view caring as part of their marriage but also as a full time job. This gives an insight into some of the conflicts experienced by caregivers.

"How long have I been caring for her? Oh, we've been married for 55 years"

(Ted, p1. 20-21)

"I always go through my wedding vows and in sickness and in health and I'm pretty certain if it was the other way round Rod would look after me so I feel this is my role"

(Joan, p2. 95-98)

"you're a caregiver just by being a wife because you care for that person"

(Ann, p6. 303)

'I'll have to go and get two single beds'

Many of the accounts reflected changes in participants' marriages which occurred as the dementia progressed. These changes were experienced as losses and impacted on the participants' emotional coping. These changes in the marriage appeared to have deep significance for the participants who were grieving these losses.

"he always always used to hold my hand when he walked with me but now because of his well you know his balance isn't so good he doesn't do it"

(Sheila, p4. 183-185)

"we don't actually sleep together that hurts me because you know a married couple that what you've always done you've slept with each other"

(Beth, p2. 79-81)

"there are a lot of things that I have to keep away you know don't tell him because he couldn't take it he wouldn't you know what I mean he's vulnerable but that is hard I've lost my husband and my friend really" (Beth, p8, 396-399) "you suddenly have to take on the role of like a parent and actually start telling people what they can and can't do or sort of having to pull them up that is the most distressing thing for me because you don't want it to be that relationship"

(Ann, p6-7. 304-307)

'What you miss'

This sub-theme is related to the last in terms of change and losses but is less personal in scope. Participants talked about how their lives had changed and that they had relinquished aspects of their lives. Participants made comparisons to their old lives and the independence and hobbies which they missed. These losses increased the caregivers' isolation and it is reasonable to assume may impact on their ability to cope with their role as caregiver.

"I can't go off for a day's fishing for example, not without arranging somebody to be here...things like that"

(Ted, p3. 113-114)

"Rod was having another stroke so from that day I stopped, I stopped overnight and I swear that if that hadn't happened I would still be on my ward because I loved it"

(Joan, p2, 83-86)

"his life has shrunk in and mine's had to shrink in to accommodate it but what worries me most is that even the small things we do now might disappear"

(Ann, p10. 469-472)

'It makes it more difficult for me'

The accounts suggest that participants were clear about what would benefit them in terms of coping, however, their spouses were resistant to this. The resultant mismatch was a contributor to the stress experienced by participants. This sub-theme links to some of the comments made in *'he tells everybody that I'm a good nurse'* in terms of whether the person with dementia had insight into their caregiver's experiences.

"he said you don't have to bother I don't want to wake you when I go back, I said it's because you don't come back that then I'm wide awake looking, wondering what you've done"

(Beryl, p5. 250-253)

"he won't have anybody in to sit with him no I don't want it, Sheila can do it, but like when the social services came round they said could they help and the chap was smashing he really was nice and he said we can get someone to come in and help you with the showering and that and he says no I'm not having somebody come in and he said well you can have male, no Sheila'll do it"

(Sheila, p5. 219-226)

"the obsessional behaviour I find that very, because I am claustrophobic unfortunately and the fact that I can't have windows open or a door open or anything like that that is my worst"

(Joan, p6. 263-266)

4) Learning

This theme focuses on the learning experiences of the participants as a caregiver for their spouse. All the participants talked about experiencing a learning curve; their experiences had shaped them. The sub-themes focus on how the participants coped with the onset of their partners' dementia and their expectations of themselves as caregivers.

'Shoulds'

The language used was of interest to the researcher. Participants frequently used the word 'should' in relation to aspects of caring, the insinuation being there is a right and wrong way to care. This burden which the caregivers placed upon themselves added to the already substantial amount of pressure they experienced.

"he gets quite belligerent, you didn't tell me, oh yes I did tell you, you know and because they say you shouldn't say, but you can't not say I have told you"

(Sheila, p1. 40-42)

"You do feel guilty, yes but you're only human because you feel you should be there 24 hours a day and you should be doing this and you should be doing that"

(Iris, p6. 265-267)

"when you've been asked for like the sixth time within an hour .. I've already said [puts on exasperated tone] yes, but then you beat yourself up about it and then later on I think I shouldn't"

(Sue, p3. 136-138)

'I've worked out a system now'

Many participants remarked on how they had learnt to cope over time and assimilated the role of caregiver into their identity. Frequently participants compared their current method of caring to the mistakes they made in the early days following onset of the illness. These comparisons highlighted a sense of currently being more in control than previously.

"I don't say oh but you should know because I think that's the worst thing you can say but I've learnt that from experience"

(Iris, p1. 22-24)

"I've had to learn to step back a little bit so I don't think now I do do as much well I do it but it's not shown do you know what I mean"

(Joan, p6. 258-260)

"I've learnt to cope with it because in the beginning I used to think oh gosh"

(Beth, p7. 354-355)

'I take each day as it comes'

This sub-theme is connected to the last and illustrates the interconnected nature of these themes. A coping strategy identified by the participants to enable them to care effectively for their spouse was to take one day at a time and not to focus on the future. Participants talked about initially planning for the future and thinking ahead but found that this was an ineffective strategy.

"it's just a way of life that you don't actually think about it do you, you get up every day is the same do what you've got to do"

(Sheila, p6. 293-295)

"I can take each day as it comes and this is what I say to my family when they phone me up and I'll say well I just take each day as it comes but I can't believe that is me saying that because at the beginning of it all I was doing what if this what if that and that wasn't helping me"

(Beth, p9. 421-426)

"I think most caregivers probably cope on a day to day basis you can't really bear to think if you start thinking I mean in your head you know what's gonna happen"

(Ann, p6. 294-296)

5) Changes

Discussion about the experience of caring for a spouse with dementia raised many themes of change for the participants. Whilst change can also be seen as an overarching framework which encompasses all the themes, it also represents some aspects in more detail.

'Now it's down to me'

The interviews revealed that there had often been distinct roles within the marriage prior to the onset of dementia and that these had shifted over time. Tackling these new unfamiliar roles was often a challenge for the participants.

"she said well I think it would be better if you did the cooking 'cause I think all men should learn how to cook...oh yeah, fine...and slowly within the last couple of years I find myself actually taking over"

(Ted, p1. 29-32)

"there was a leak in the conservatory so I'm there filling it all in you know it's all the responsibility of where he would do it, it all falls on me and I'm blocking my guttering and one thing and another"

(Iris, p3. 116-119)

"you suddenly have to take on the role of like a parent and actually start telling people what they can and can't do or sort of having to pull them up"

(Ann, p6-7. 304-306)

'He was interested in cooking'

Participants experienced their spouses undergoing many changes since the onset of their dementia. The change in their interests represents a shift in their identity and sometimes loss. Beth's husband has found new interests to replace hobbies in which he is no longer able to partake whilst others experienced their spouses doing less and less.

"she doesn't seem to be interested in very much...she doesn't do very much at all and knowing that she was quite active"

(Ted, p1. 15-17)

"when he can't get down the workshop if he doesn't have anything to make or if he hasn't got a little job in the garden to do he's bored you see so he'll pick that up and he sits there and he's doing that nearly all evening the puzzle"

(Beth, p3. 108-112)

"he was always sociable and laughing and stories and that see that was another sign really before that suddenly I realised he'd be sat there and I was doing all the talking"

(Ann, p4. 162-165)

'It's gradually increased'

Linked to the themes discussed in *learning,* participants identified that caring evolves over time and the caregiving process is not static. One of the difficulties of caregiving is that the dementia continually changes and progresses and the caregiving process needs to change and adapt accordingly. Sometimes this made caregiving harder, sometimes it made it easier for participants.

"every time he comes back but for the last six months I've dozed off and he's not there"

(Beryl, p5. 242-244)

"whereas now it's a different kind of caring in a way because he is more, he is less mobile so I don't worry about that but there are other things I have to do instead so it's sort of swings and roundabouts"

(Sue, p4. 195-198)

"I have to accept that he's changing but that's the most these changes happen you know"

(Ann, p8. 360-361)

"this disease is progressive so who knows what the future holds"

(Ted, p4. 164-165)

'Good days and bad days'

This sub-theme focuses on the day to day situational changes which were experienced as challenging by caregivers. Participants frequently described both themselves and their spouses as having good days and bad days and that this affected their ability to cope. This daily variability and unpredictability takes its toll on the emotional coping resources of caregivers.

“I have good days and bad days, some days it depends if you’ve had bad nights”

(Beryl, p5. 356-237)

“and then last night he got up and I thought I wonder what’s going to happen”

(Beryl, p6. 256-257)

“it sums up that not one day is the same as the next you never know what’s going to pop up because of their reactions”

(Beryl, p6-7. 305-307)

Discussion

The aim of this study was to give an insight into the experiences of eight caregivers and their perception of the coping style shown by their spouse with dementia. The aim was to explore and understand participants' experience and meaning making of being a caregiver for their spouse. This study highlights common themes and similarities between participants' accounts and also highlights differences between their experiences. These differences were apparent in terms of the behaviours, coping, and emotional demands presented by their partners and their own coping strategies and reactions to their spouse. This study indicates that although there may be some commonalities in the experiences of the caregivers interviewed, it is essentially a unique experience. Concepts of experience, coping and change were present in participants' accounts and suggest that the caregiving process is mediated by learning and adjusting to these changes whilst coming to terms with losses and unpredictability of the future as a means of coping. Some of the participants interviewed felt that they were coping better now than at the onset of their spouse's diagnosis and this process of adjustment may contribute to why. It is likely that numerous factors affect how caregivers experience their role and how they cope with the demands of caregiving. The reasons for these individual differences in coping are not explored within this study but may be linked to personality, environment, relationships, past experiences and any number of psycho-social factors.

Summary of findings

Several key themes associated with the experience of caring for and coping with caring for a spouse with dementia were identified in this study. Overarching themes of experience, coping and change were present throughout the participants' accounts and five super-ordinate themes were identified by the researcher. These five themes: *patient factors, caregivers' experiences, relationships, learning,* and *changes* are interlinked and are comprised of numerous sub-themes. It is important to note that individual differences were present throughout the transcripts.

These themes are presented in a hierarchy with sub-components in order to produce a coherent account of being a caregiver for a spouse with dementia. However it must be noted that these themes are interactive and intrinsically linked. For example issues of learning cannot be separated from issues of change as learning occurs through change and learning necessitates change. Considering the themes described as a reciprocal process rather than separate constructs therefore provides a better insight into participants' experiences. In addition it was evident from participants' accounts that different strategies and experiences were described at different times and were not mutually exclusive. For example, caregivers might perceive their spouse as being reliant and dependent but at the same time their spouse may be trying to retain independence in some areas of their life. One strategy does not preclude the other.

These themes could have been organised into a framework focusing on the cognitive, behavioural and emotional components to align it with CBT. However this may have been detrimental to the more general concepts of experience. The researcher adopted a flexible focus in keeping with the philosophical stance of IPA which allowed themes to emerge through participants' accounts and reflects the richness of the data. IPA is a joint product of both researcher and participant. The researcher is attempting to capture something of the lived experience of the participants but it inevitably involves interpretations on the part of the researcher (Smith et al, 2009). With this in mind the researcher chose the themes which resonated most with her in terms of making meaning of the participants' accounts. Inevitably there are any number of themes which could be presented. The themes presented in this study reflect the participants' experiences of caring for a loved one, the losses and challenges this entails (both for them and their spouse), the impact of caring on their everyday lives, their relationships, their emotions, the changes that have occurred, and what they have learnt during the process. The themes relating to changes in the married life of the participants and the losses experienced in the quality of their relationships particularly resonated with the researcher. The researcher perceived these losses caused by the dementia as one of the most significant.

Previous research on the experience of caring for people with dementia

It is interesting to consider how this current study relates to findings of previous research on caring for individuals with dementia. A number of studies have found that caregivers experience high levels of stress, anxiety and depression (Graham et al, 1997; Proctor et al, 2002; Schreiner at al, 2006) and this research reflects these findings. Participants' accounts revealed struggles with low mood and anxiety, some participants were tearful during the interviews, and two participants were taking anti-depressant medication. The quantitative data revealed that four of the eight individuals interviewed scored within the clinical range on the DASS with regards to depression and three scored within the clinical range on the DASS with regards to anxiety.

Pearlin et al's (1990) research concluded that in conditions such as dementia, caregiving can be so demanding that it can occupy the entirety of the relationship. The participants' accounts were rich in data which supports this finding with participants stating that the caregiving role occupies 24 hours a day, seven days a week and that the role has no respite. Accounts suggested the change in relationship from spouse to caregiver pained the individuals interviewed who didn't want to 'parent' their spouse but felt that their relationship had changed to reflect this form of care.

Pearlin's model of caregiver stress may also account for the individual differences noted in the participants' accounts of their experience. Whilst there were common themes across transcripts, each account was unique and reflected the different ways in which caregivers coped with and viewed their experiences. Pearlin et al stated that background and context, primary and secondary stressors, mediators and manifestations of stress all contribute to the stress and burden experienced. Participants' accounts reflected these differences; two individuals had experienced recent bereavements, one had a close and supportive family, two had a supportive circle of friends, two felt isolated, one was experiencing financial hardship. In addition, the presentation and progression of the spouses' illnesses all differed. These subjective differences expressed by the participants fit with Pearlin et al's understanding of caregiver stress.

One of the findings observed in the current study resonates with previous research by Whitlatch (2001) and Kitwood (1997). They found that when individuals took an active role in their care it could be problematic for some caregivers. In accordance with this finding one participant in the current study stated that she currently found it easier to care for her husband because he was more passive now than he was at the onset of his illness. He had previously been more active in his care whereas he now allowed his wife to care for him. Similarly two individuals in the current study noted that one of the sources of stress was their spouse offering to help and trying to maintain independence. However other individuals in the study did not find this problematic. This illustrates the uniqueness of individuals' experiences.

These findings link to the initial aims of this research and ideas about whether being more active is linked to not accepting limitations caused by dementia. It is interesting to consider why Whitlatch's research found that individuals taking an active role in their care caused problems for their caregivers. This could be due to individuals fighting against their diagnosis and pushing themselves to remain independent in accordance with their prior sense of self. In contrast, this independence could result from individuals accepting their diagnosis and trying to remain active within their new sense of self. These individual differences link explicitly to Clare's (2003, 2009) research which revealed different coping responses in dementia depending whether individuals adjusted their sense of self following a diagnosis of dementia or tried to maintain continuity with their prior sense of self.

This study was informed by Clare's (2003, 2009) qualitative research into the coping responses of individuals with dementia. Whilst the present study was not able to identify the participants' spouses on Clare's continuum of coping responses from self-adjusting to self-maintaining, it did highlight some similar themes. Clare (2003) had hypothesised that some individuals with dementia cope by confronting their diagnosis and difficulties, whilst others minimize the threat by denying these difficulties. These patterns of acceptance and avoidance with regards to diagnosis and onset of difficulties were perceived by the participants with regards to their spouses' reactions. Whilst this was not present in sufficient detail to further Clare's findings, it does offer insight into the coping mechanisms utilised by individuals.

Previous research into caregiver stress has emphasised the importance of support in reducing carer burden (Commissaris et al, 1995; Zarit, 2008). Social, family, and professional support have been found to be powerful mediators of stress and Pearlin et al's (1990) stress process model of caregiving highlights the impact of support on outcomes for the caregiver. Therefore it is surprising that issues around social and professional support did not contribute to a theme in this study. Some participants talked about support and that they had access to services which they viewed as positive and helpful. Others however stated that they had felt frustrated by agencies and the way that older adults were treated as a whole. Some participants did not mention support at all during the interviews and subsequently the researcher did not include issues of support as a theme.

Common themes raised in previous research on dementia and caregiving are those of loss and relationships which have been echoed in the present study (Cohen, 2000). Previous research has focused on interpersonal factors, with relationships and roles being highly salient (Zarit, 2008). The social context within which caregivers and their spouses exist and the often resultant social isolation and impact on role are reflected in the literature and within the themes noted in this study.

Limitations and methodological issues

This piece of research has utilised an IPA methodology which has its limitations as it is a subjective account and reflects the assumptions and biases of the researcher. The interviews reflect the experiences of the eight individuals interviewed and how their narratives were interpreted by the researcher. As with all IPA research the findings are not generalisable to a wider context, instead they reflect the unique experiences of the individuals interviewed. The aim of the study was to gain rich detailed accounts of the participants' experiences in order to inform the researcher's understanding. The aim of the IPA interview was to facilitate an interaction which allowed the participants to tell their own story in their own words. It is advised that the researcher asks no more than ten questions in order to facilitate this interview (Smith et al, 2009). A limitation of this open structure is that the researcher does not ask direct or closed questions which means that there may be elements in which the researcher is interested but is not able to facilitate. Consequently, although the aim of this study was to identify the coping responses of individuals with dementia and ascertain how this affected their spouses' experience of caregiving, this information was not gained in sufficient depth to enable the researcher to gain an understanding of this topic. The questions included in the interview schedule may have been responsible for this and would need to be amended in order to facilitate more explicit discussion in this area. Similarly the researcher was new to using an IPA methodology and this inexperience may have resulted in her not gaining an understanding of the topic intended.

The use of qualitative methodology can be considered a limitation with regards to the original aims of the study. A quantitative method utilising a correlational design may have yielded interesting results in terms of categorising the spouses by rating interviews with them on Clare's (2003, 2009) spectrum from self-maintaining to self-adjusting. Currently there is no quantitative measure of coping responses validated for use with an older population with dementia. Validating a measure for use with this population may produce interesting results with regards to coping mechanisms and their impact on caregiver burden. However whilst quantitative data produces more generalisable results, it loses the rich and unique data produced by qualitative data.

There may have been some bias in the recruitment procedure utilised in this study. The researcher accessed the participants through a memory support group. The memory support group was attended by individuals who had access to local services and may not therefore be representative of all caregivers of individuals with dementia. Participants were also volunteers and the fact that they both volunteered and had the time to participate may set them apart from other caregivers. Additionally seven of the eight caregivers were female. Had more males been interviewed then different themes may have materialised. However, research by Wijeratne (1997) found that the majority of caregivers tend to be female and aged 60 years or older so perhaps the sample was representative. Again, caregivers of younger individuals with early onset dementia may have different experiences of caregiving.

It is also important to consider the stage of dementia experienced by the caregivers. The researcher interviewed caregivers of individuals with mild dementia only and different themes may have emerged if caregivers had spouses in the later stages of dementia. The mild stage was chosen for this study in line with previous research (Clare, 2001; 2002; 2003;

Clare et al, 2005; 2006) and because in this mild stage caregiving is less concerned with behavioural disturbances and physical care. This was an important consideration given that the researcher hoped to identify cognitive coping styles.

It is important to consider that the researcher was sometimes the only person to whom the participants had spoken about their experiences of caregiving. Some of the individuals interviewed were tearful and admitted that they hadn't spoken to anybody about these issues before. Therefore they may have presented as more emotional because the process was in some way cathartic for them. Perhaps individuals who attended counselling, had previously spoken of their experiences, or had more support would have presented different narratives and experiences of emotional coping.

With regards to cultural issues, all participants in this study were of white-British ethnic origin as was the researcher. Given that the findings of IPA are interpretative this may have implications and reflect culturally embedded ways of experiencing and coping with progressive illness such as dementia. The social context experienced by both the researcher and participants may affect the way dementia is viewed, thus individuals from other cultures may have differing experiences.

Relevance to clinical field

This study was explorative in nature and aimed to provide a qualitative account of the experiences of caregivers. The researcher considers the IPA methodology utilised in this study to be compatible with the practice of clinical psychology. Within clinical psychology clinicians seek to gain an understanding of the unique and subjective experiences of individuals and their meaning making of these experiences. IPA takes a similar approach to understanding participants and appreciates that the findings are a joint product of both researcher and participants, much as formulations in clinical psychology are a collaborative effort of both clinician and service user. Additionally, the concept of therapeutic alliance was also important to the researcher when interviewing participants. It was important for the researcher to build rapport in a manner similar to that with a service user in a clinical setting (Yardley, 2000). Therefore the researcher considers the methodology used in this study to have parallels with clinical practice in terms of valuing the uniqueness of experiences, adoption of a person centred approach, reflexivity, the relationship established, and the influence and interpretations of the researcher.

Clinical implications

The themes identified in this study have important clinical implications for the future. Currently 80% of the elderly population with long term conditions including dementia are cared for by family members. As the prevalence of dementia is anticipated to increase because people are living longer, so too will the burden and responsibility felt by caregivers. The Department of Health (2001) advocates the involvement of service users in care planning and service development and currently the views of individuals with dementia and their caregivers appear to be underrepresented. Therefore qualitative research elicited by studies such as this one help to inform services of the needs of caregivers. The National Institute for Health and Clinical Excellence (NICE, 2006) recognises that dementia is associated with complex care needs which can challenge the skills and capacity of caregivers and services and advocates maximisation of benefits for individuals with dementia and their caregivers. Currently services run groups for caregivers in order to enhance understanding and offer support in caring for an individual with dementia. The individuals interviewed for this study had experienced input from such services but were still struggling emotionally and creating rules for themselves about what they should or should not be doing. These strict rules meant that the participants often felt that they were failing by not keeping to these self-imposed rules.

This study was inconclusive about the impact of support from services. Issues around social and professional support did not contribute to a theme and were not widely discussed by participants despite the literature suggesting that support is an important mediator of caregiver stress. The reasons for this are of clinical relevance because although some participants viewed input from services as positive it didn't appear to affect overall burden. Services perhaps need to offer more intensive and personalised support to caregivers over a longer time period. Currently groups are run for caregivers early in the onset of their spouses' diagnosis and caregivers may benefit from repeated group support.

Conversely, social and professional support may have had a protective impact on the participants in this study despite the participants not talking about it. The issue of support may not have been widely discussed by participants because the questions asked by the researcher may not have facilitated this discussion. The interview schedule used by the research contained only ten questions and may have been structured in a manner which prevented support from being highlighted. The available literature suggests that support from services and multicomponent interventions are beneficial for caregivers. For example, a recent study by Olazaran et al (2010) found that nonpharmacological therapies can improve the quality of life for both caregivers and individuals with dementia. Olazaran and colleagues performed a systematic review and meta-analysis of the effects of nonpharmacological therapies in Alzheimer's disease and related disorders to produce robust support for the impact of service involvement. Unfortunately, qualitative data gained from the current study did not provide the researcher with an understanding of how services can best support the coping of caregivers and their spouses.

It is vital that knowledge about the stressors and variables which affect levels of caregiver burden and coping are utilised in service development in order to support and meet the needs of caregivers. Qualitative research produces a rich insight into these experiences and can be used to influence service development.

Future research

Given that this study did not fulfil its research aims it would be useful to conduct further research in order to enhance understanding of caregivers' experience of their spouses' coping style in dementia. The interactions of the caregiver-patient dyad were apparent in this study but are little represented in the literature. Similarly the impact that the onset of dementia has on the marital relationship is under-represented in the literature but was a salient theme in the current research. Future research could focus on these areas in order to increase understanding of the multitude of stressors affecting caregivers.

The role of support and interventions offered by services would be worth investigating in more detail in future research. The results of this study did not allow the researcher to draw conclusions about how professionals can best support the coping responses of both the caregiver and the individual with dementia in a way which is mutually beneficial.

However this aim is achievable and would hopefully yield results which could be used to guide services.

Given that the majority of participants in the current study were female, conducting future research with male participants in order to gain an understanding of their experiences as caregivers would be valuable. Additionally, it is important to bear in mind that the current study represents the experiences of eight participants at one point in time. Future research could take a more longitudinal stance and explore how coping fluctuates over time. The themes of learning and change over time were salient in the current research and future studies could yield interesting results in this area.

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List of Appendices

Appendix A

Rational for Methodological Choice

There were a number of reasons why a qualitative study using Interpretative Phenomenological Analysis (IPA) was chosen to investigate the research phenomenon. These are outlined below:

- The aim of the current research was to explore, in detail, the experience of caregivers of people with dementia. In particular, the research aimed to explore caregivers experiences with regards to their perception of their spouses' style of coping with dementia. There is currently very little available research in this area. Therefore this study aimed to be exploratory in nature given that research in this area is in its infancy. The use of measures to investigate coping was not appropriate as currently there are no standardised and validated measures of this construct for use with older adults in existence. In addition, qualitative methods offer rich detailed accounts which would not have been acquired if quantitative measures were available.
- The constructs of experience and coping lend themselves to exploration using qualitative analysis. They are processes which are underpinned by personal and unique experiences.
- IPA was considered to be the most appropriate method of qualitative analysis and its key features are compatible with psychological models and theory. The process of IPA entails analysing individual accounts in their entirety. This retains the uniqueness of the individuals' transcripts prior to making links and interpretations across

transcripts. Through this in-depth analysis themes emerged which were then formulated into a hierarchical construct of these themes. This method of formulation felt compatible with the practice of clinical psychology and reflected the person-centred approach used in clinical settings whereby clinical psychologists hypothesise and develop formulations collaboratively with clients in a therapeutic context.

- A number of other qualitative approaches were considered in addition to IPA. IPA is considered appropriate when the researcher has an idea of the area they wish to explore. It focuses on personal meaning and sense-making in a particular context for people who share a particular experience, such as caregiving. Other qualitative methodologies would not have been as appropriate. Thematic analysis, for example, is useful if the researcher knows very little about a research area and therefore wants to identify and report patterns in the data. In the current study the researcher wanted to explore a specific area; the relationship between caregiver and spouse. Similarly grounded theory is useful if the researcher seeks to analyse and develop a theory, and identify which factors influence a given phenomenon. This was not the aim in the current study so was not considered an appropriate option. Discourse analysis focuses on the language and phrasing utilised by participants and is useful if the researcher seeks to understand how participants talk about a given phenomenon. Narrative theory investigates how a life course is constructed as a story and focuses on story structures utilised in sense making. The researcher therefore identified IPA as the most appropriate methodology given the aims of the study.

Appendix B

Carers' experience of their spouse's coping style in dementia: a study using Interpretative Phenomenological Analysis

LETTER OF INVITATION TO PARTICIPANT (Version 2)

My name is Lindsay Walker and I am a Trainee Clinical Psychologist at the University of Southampton. I am undertaking my thesis for a doctorate in clinical psychology and am inviting you to take part. My thesis will be titled 'Carers' experience of their relative's coping style in dementia: a study using Interpretative Phenomenological Analysis' and will look at the experiences of carers, like you.

The purpose of this study is to learn more about the experiences of carers in caring for their loved one with dementia. Whilst research has looked at the level of stress associated with being a caregiver, little has been undertaken into how the coping style of the person with dementia impacts on this stress. I am interested in finding out what your life as a carer is like and how the person you care for has reacted to their illness and losing their independence. I am interested to find out how their way of coping with their illness impacts on your experience of being a carer.

This study involves an interview which will last approximately one hour. This interview will be tape recorded. I will also ask you to complete two brief questionnaires which will take between five and ten minutes. You may withdraw your participation at any time. Personal information will not be seen by or released to anyone other than the researchers involved in this study. The results of the study will not include your name, date of birth or any other identifying characteristics and your confidentiality will be maintained.

If you are interested in taking part in this study then please contact your care coordinator or myself using the details below:
Lindsay Walker [redacted]
Regards
Lindsay Walker, Trainee Clinical Psychologist

Appendix C

Study title: **Carers' experience of their spouse's coping style in dementia: a study using Interpretative Phenomenological Analysis**

INFORMATION SHEET (Version 3)

My name is Lindsay Walker and I am a Trainee Clinical Psychologist at the University of Southampton. The purpose of this study is to learn more about the experiences of carers in caring for their loved one with dementia. Whilst much research has looked at the level of stress associated with being a caregiver, little has been undertaken into how the coping style of the person with dementia impacts on this stress.

This study will use semi-structured interviews in order to gain information about your personal experiences and these will be tape recorded and then transcribed onto a computer at a later date. I will then examine all the transcripts that I have gained from carers in order to look for themes which emerge from the interviews. The interviews will give me a rich and detailed picture of your experience. These interviews will take place at [redacted] or at your home, whichever you prefer, and will take approximately one hour.

The study also makes use of two questionnaires, the Zarit Burden Interview (ZBI) and the Depression, Anxiety and Stress Scales (DASS). The ZBI looks at how carers perceive strain and the DASS looks at mood. The questionnaires will take approximately ten minutes to complete. Data from these questionnaires will contribute to my understanding of carers' experiences.

Personal information will not be seen by or released to anyone other than the researchers involved in this study. The results of the study will not include your name, date of birth or any other identifying characteristics and your confidentiality will be maintained. In alignment with the NHS Code of Confidentiality and the Data Protection Act (1998) there will be pseudonymisation of data. Codes or other unique references to information will be used so that the data will only be identifiable to the researcher who will have access to the key or index. Following the study the tape recordings of the interview will be wiped. If you have any concerns about the study then you can contact the research governance office at the University of Southampton on [redacted].

Sometimes talking about aspects of caring and the effects of dementia can be distressing. I will be available to all participants following the study if you feel that you need to speak about any distress experienced. Participation is voluntary and you may withdraw your participation at any time.

Thank you for time.

Contact details for the researcher:

Lindsay Walker
c/o University of Southampton
[redacted]

Lindsay (direct): [redacted]

Appendix D

Study title: Carers' experience of their spouse's coping style in dementia: a study using Interpretative Phenomenological Analysis

CONSENT FORM (Version 3)

Researcher name: Lindsay Walker
Study reference: [redacted]
Ethics reference: [redacted]

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (date/version no.) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research project and agree for my data to be used for the purpose of this study	☐
I agree to take part in the interview with the researcher	☐
I consent to the researcher audio recording the interview	☐
I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected	☐
I agree for my data to be stored anonymously for the duration of the study	☐

Name of participant (print name)……………………………………………………………

Signature of participant……………………………………………………………………

Date……………………………………………………………………………………………

Appendix E

Study title: **Carers' experience of their spouse's coping style in dementia: a study using Interpretative Phenomenological Analysis**

DEBRIEFING SHEET (Version 1)

Thank you for taking the time to be involved in this study.

I appreciate that discussing your experience of being a carer and talking about your loved one with dementia can be distressing. If you feel that you would like to talk about the impact that the study has had on you, or if you would like to know more about the study, then please feel free to contact me using the details below:

Telephone: [redacted]

E-mail: [redacted]

Lindsay Walker
Trainee Clinical Psychologist
University of Southampton

Appendix F

QUALITATIVE STUDY: DRAFT SEMI-STRUCTURED INTERVIEW SCHEDULE

(Version 2)

1. How did you first become aware of the difficulties with your husband's/wife's memory?

2. How long have you been a caregiver for your husband/wife?

3. How has being a caregiver affected your daily life? (Prompt: It may be useful to go through the day from the time they wake up).

4. How does your husband/wife cope with their illness? (Note how the participant refers to their coping style and use their terms). Can you tell me about how they compensate for their difficulties?

5. How would you describe their coping style with regards to dementia?

6. Has their way of coping changed since their diagnosis?

7. Can you tell me about how this has impacted on you?

8. Do you think your way of coping with caring for your husband/wife has changed over time? If it has – how has it changed?

9. Can you tell me about what is most difficult or stressful for you when caring for your husband/wife?

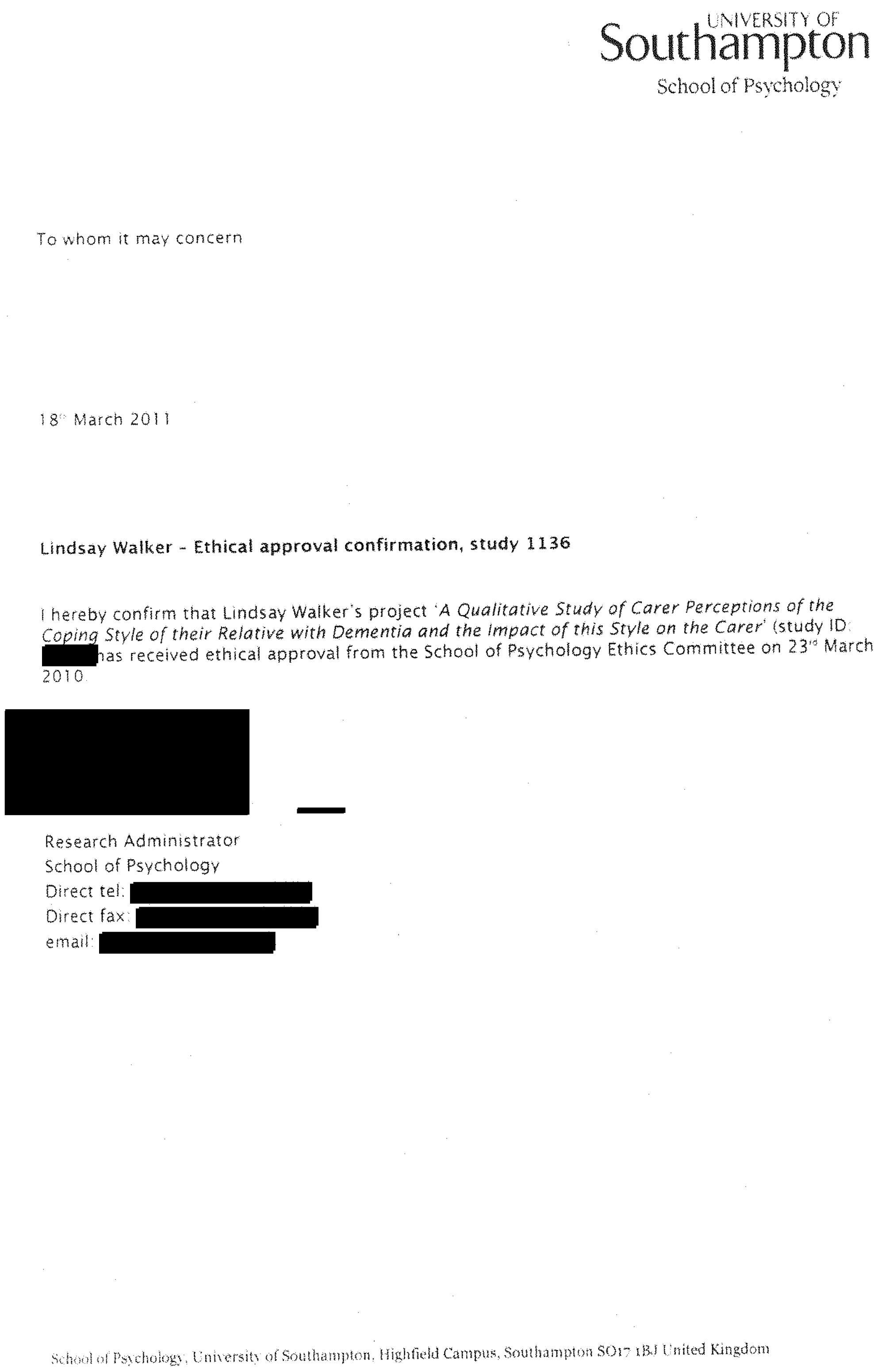
10. What do you think would make it easier for you to care for them? What could services offer to support you?

    If necessary, questions will include prompts: eg. can you tell me a bit more about that?/ What do you mean by *****?

NB: Ten Questions have been suggested based on recommendations made by Smith, Flowers and Larkin (2009) who suggest that between six and ten open questions will tend to occupy between 45 and 90 minutes of conversation.

Appendix G

University of Southampton Ethical Approval



UNIVERSITY OF
Southampton
School of Psychology

To whom it may concern

18th March 2011

Lindsay Walker - Ethical approval confirmation, study 1136

I hereby confirm that Lindsay Walker's project '*A Qualitative Study of Carer Perceptions of the Coping Style of their Relative with Dementia and the Impact of this Style on the Carer*' (study ID: [redacted] has received ethical approval from the School of Psychology Ethics Committee on 23rd March 2010.

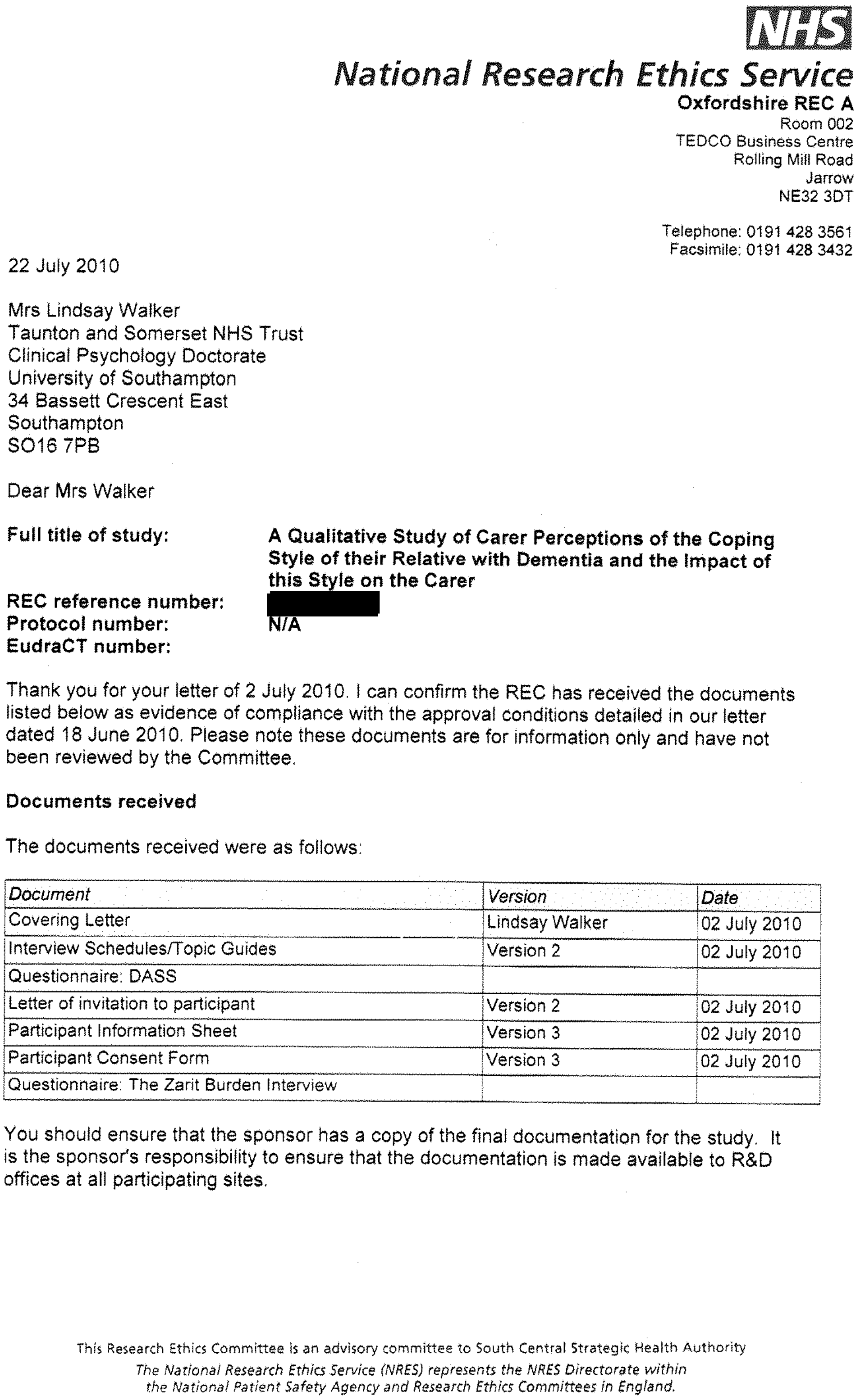
[redacted] [redacted]

Research Administrator
School of Psychology
Direct tel: [redacted]
Direct fax: [redacted]
email: [redacted]

School of Psychology, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom

Appendix H

Local NHS Research Ethics Committee Approval



NHS
National Research Ethics Service
Oxfordshire REC A
Room 002
TEDCO Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3561
Facsimile: 0191 428 3432

22 July 2010

Mrs Lindsay Walker
Taunton and Somerset NHS Trust
Clinical Psychology Doctorate
University of Southampton
34 Bassett Crescent East
Southampton
SO16 7PB

Dear Mrs Walker

Full title of study:	**A Qualitative Study of Carer Perceptions of the Coping Style of their Relative with Dementia and the Impact of this Style on the Carer**
REC reference number:	[redacted]
Protocol number:	N/A
EudraCT number:	

Thank you for your letter of 2 July 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 18 June 2010. Please note these documents are for information only and have not been reviewed by the Committee.

Documents received

The documents received were as follows:

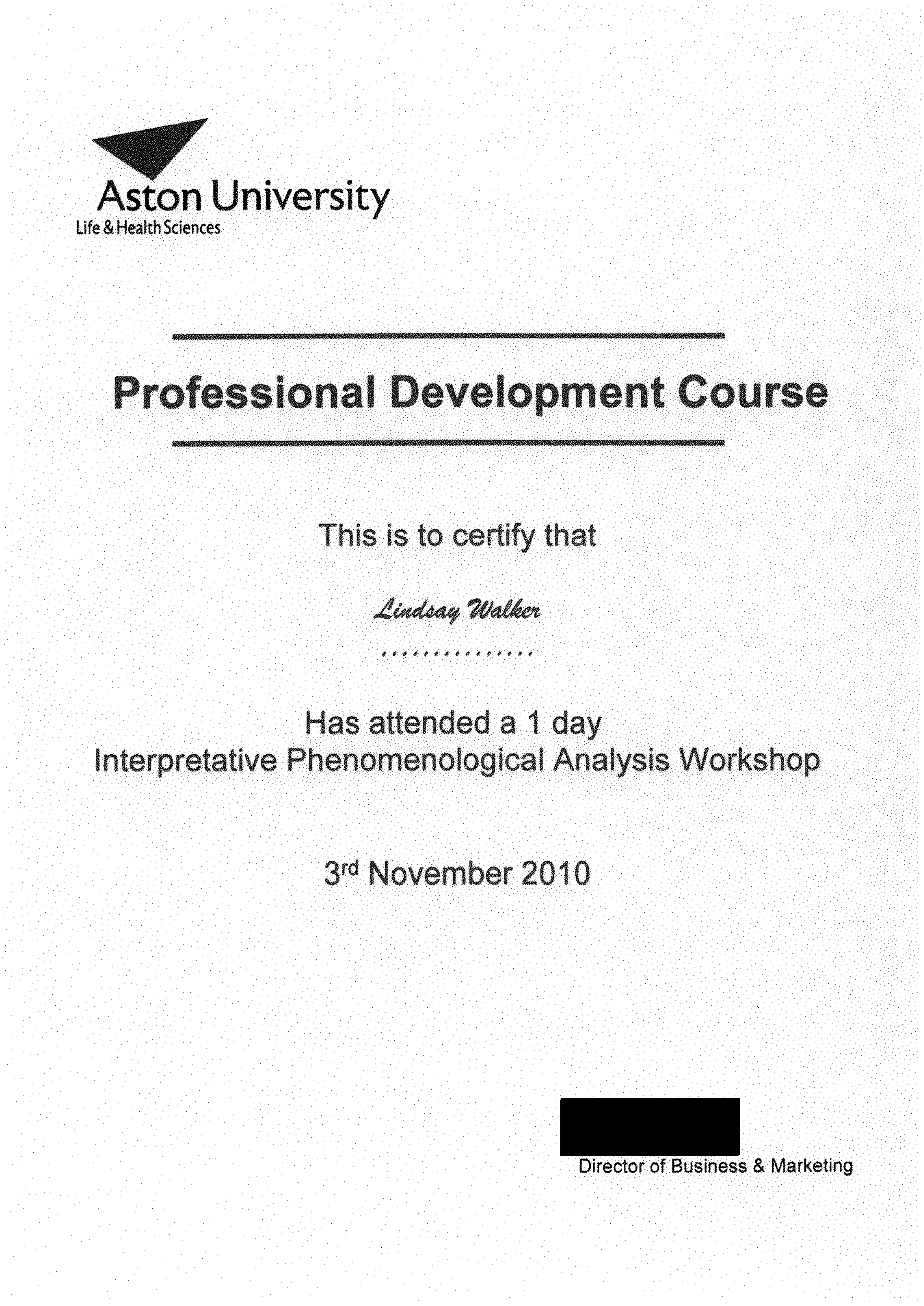
Document	*Version*	*Date*
Covering Letter	Lindsay Walker	02 July 2010
Interview Schedules/Topic Guides	Version 2	02 July 2010
Questionnaire: DASS		
Letter of invitation to participant	Version 2	02 July 2010
Participant Information Sheet	Version 3	02 July 2010
Participant Consent Form	Version 3	02 July 2010
Questionnaire: The Zarit Burden Interview		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

[redacted]

Appendix J

IPA Workshop Details and Confirmation of Attendance



Aston University
Life & Health Sciences

Professional Development Course

This is to certify that

Lindsay Walker
....

Has attended a 1 day
Interpretative Phenomenological Analysis Workshop

3rd November 2010

[redacted]
Director of Business & Marketing

Appendix K

Reflexive Account of the Researcher's Perspective

I am beginning to notice common themes throughout the interviews already. The idea that it is lonely, frustrating. My interviewees have been supported well by One Community and the Memory Club but there is a sense that it was hard in the beginning and there wasn't the support initially.

Frustration with spouses – it's not their fault but it is annoying. Some people saying that they can't help saying 'I've already told you this'. Sue doesn't however. Also, there seems to be so much physical stuff alongside the dementia. And the need for routine, structure and the moodiness/snapping surprised me.

Sense of unfairness of it all. Makes me worry about my future. What if this happens to me or to my husband? Or my parents. It is worrying. I can understand why people turn away.

Recruitment – I found this hard. I would go to the memory club and present to carers but they didn't volunteer. If I approached them individually then they were more keen. I began to feel like I was harassing them though – I did not enjoy recruiting them at all. I have only managed to get one male participant - it is a shame. I approached another male but he said that he was too busy.

Friendships and support. Much like bereavement people don't understand and are scared so they avoid. But this lack of support is devastating for the carer. Several people said this. Made me think of bereavement. More info needed by general public so that this doesn't happen.

"First, it is important to recognise that doing this type of research is personally demanding in a number of ways: talking with patients about serious health conditions can, of course, be distressing.." (Smith, Flowers & Osborn, 1997).

Beryl:
Clearly Edward was an intelligent man. He is still able to go out for walks so the physical care isn't so much of an issue. Perhaps his intelligence masks/compensates for the Alzheimer's to a degree.
Beryl was able to see how all the common features of caring – anger, frustration, depression, anxiety – all reflected her own experience.

Ted:
Seemed to be coping ok – there didn't seem to be too much of an emotional impact. More concerns about what happens if he goes out and she falls. He appeared to take it all in his stride to a certain degree. Perhaps it is harder to admit emotional vulnerability when you are an older male of his generation – you just get on with it.

Sheila:

Everything was clearly just below the surface. Sheila became tearful on a few occasions and she has had other losses and difficulties in the family to deal with. Paul also has asbestosis which is an added difficulty. She seems to be heavily relied on and only just seems to be coping. I don't think it would take much to tip her over the edge. Talked about respite. It seems that respite would be the one thing to really help the carers but their spouses won't have it - they don't want to be cared for by anyone else. I found interviewing Sheila quite emotional – she's young, attractive and should be enjoying her retirement but instead her life is so hard.

Sue:

Sue seemed to cope well and appeared to be managing. She did have several mornings to herself though as Kimberley Care took John out. Is it this respite that makes it easier to bear or was it the fact that John has always had epilepsy so Sue is used to caring. I didn't feel the emotional pull that I experienced with Sheila and Beryl. It felt less tragic. Perhaps this is due to expectations. John has always had poor health?

Iris:

Being a carer is the loneliest place in the world.

Financial restrictions – emphasis that this is important.

Family matters were also causing stress. This actually seemed more important and distressing than the Alzheimer's. Granddaughter died at 21 days and Iris has a strained relationship with her daughter. Daughter also doesn't bother with Tom. This causes problems. Or is it just that Iris is busy worrying about everything as a distraction from worrying about the Alzheimer's. It could be her coping strategy? This strategy is equally exhausting but perhaps it works for her?

Joan:

I found this very difficult. Joan has had to cope with so much due to Rod wanting to kill himself and that her daughter has pulled away and said that as far as she is concerned her dad died when he had his stroke. Rod's personality has changed and he is quite unpleasant to Joan. He sat in on some of the interview and was quite nasty to her. She said she finds it hard and it upset her. I feel that Joan is coping but that it wouldn't take much to push her over the edge. Am relieved that she is having counselling after xmas. I am worried about her cancer diagnosis – who would look after her? Who would look after Rod if she isn't able to? I probably related to Joan as she has a similar way of coping to me and is a similar person to me.

Beth:

I enjoyed this interview and felt that I had a bond with Beth. She seemed like she was managing to care for Terry well and had accommodated these stressors into her life. She became upset when she said that they had had a good marriage and it felt like she had lost her best friend. Beth said that she hadn't said this to anyone before but that saying it helped her although it was upsetting. I could sense the genuine love between her and Terry and this was still in the relationship. There was a lovely respect for Terry which I think helps her to cope with the caring role.

Ann:

From our earlier conversation on the phone the frustration is apparent that there just isn't enough being done. Feelings of being rejected by the government and that older people just don't matter. This interview was difficult. Ann seemed quite defensive and was clearly teetering on the edge in terms of her emotions. She was quite teary and tried to suppress it but I felt that she was more upset than she let on. She said that talking about it upsets her and that she copes by pushing it down and just getting on with things. She almost seemed to keep excusing herself when filling in the ZBI and DASS saying that she had seasonal affective disorder and that would affect the outcome and that all the items were repetitive and could apply to anybody. She was quite critical. I wondered if she was trying to excuse her feelings because the idea of seeing the reality of her struggle was too much. Clearly the idea that Bob would get worse was very hard for Ann and she didn't seem to have accepted this as yet.

Appendix L

Principles of Quality Qualitative Analysis as outlined by Yardley (2000)

Yardley (2000) presents four principles which can be used flexibly as a guideline to assess the quality of a qualitative project. These include;

1. *Sensitivity to context* i.e. developing a sophisticated relationship between research findings and the existing literature. This highlights the importance of the context of theory, taking into account previous research in the chosen topic area, or research employing similar methodology. Also important when considering sensitivity to context is the social and cultural environment in which the research is conducted.
2. *Commitment and rigour* i.e. prolonged engagement with the topic and developing competence and skill within the methods used. Rigour refers to the resulting completeness of the data, this is related to the adequacy of the sample in terms of its ability to supply all information needed for a comprehensive analysis.
3. *Transparency and coherence*. This refers to presenting the analysis process in a clear manner and detailing every aspect of data collection and analysis. It is also important to highlight excerpts of transcript to the reader for they themselves to discern the analysis process.
4. *Impact and importance* i.e. as with any piece of research it can be judged on its impact and utility in the clinical field. This is important when discussing any type of research and research's usefulness can often be defined by it's value to those to which it was intended.

Appendix M

Example of analysed transcript

Descriptive	Interview Transcript: Joan re Rod	Interpretative
Stroke affected memory last couple of years Memories locked away	*How did you first become aware of Rod's difficulties with his memory?* Well when he, after he had his second stroke his memory was poor but what with the speech therapy and the physio and that it seemed to help and come back but um I would think about the last couple of years really, his um memory I think it's there it's locked away it takes him a little while to come to the fore	Stroke lead to poor memory – not lost, just hard to recall
mpulsive behaviour irritable + frustrated compares to before stroke	*What differences have there been in the last couple of years then?* um compulsive behaviour um agitation um I think because he's he know he wants to do it but he can't do it like he used to, and Rod lives in the past, he had a very responsible job and he always calls it in the olden days I used to be able to do so and so and I think that still gets under his skin which is understandable um [....] I don't know [....]	compares to before stroke Symptoms, agitated, frustrated, compulsive behaviour
blames me for things on taking over – upsets Rod not accepted his dementia trying to claw back understandable more difficult for me walking on eggshells even keel obsessional behaviour	seems to blame, I get the feeling he blames me for a lot of things um because he used to do these things and can't do them now and I've literally had take over everything um gets him cross but I suppose not cross but gets upset the fact he can't do it um ... he hasn't accepted the fact that he's, I don't think he's accepted it very well, that he has got dementia, he's still trying to claw back things which I suppose is understandable but it makes more difficult for me really um I personally I feel I'm walking on eggshells all the time to try and keep an even keel but it doesn't always happen um as very obsessional behaviour is quite marked um we have to have all the windows locked and closed they are checked I don't know how many times a day I mean secure do you think?	blaming & resentful of Joan doing things Denial Struggling to accept diagnosis & change but makes it harder for Joan Treading on eggshells around the the Joan – understanding, insight
4 years	*So how long have you been caring for Rod?* I think about oh dear six years, I was 72, so no four years	
excuse for apologetic – defence? lose my cool Tired 'in my defence' on the go all day – full day barely sit down Day services 2/7 respite – 1 wk poor health Working 14-15 hrs eat on the hoof	*How has caring for Rod affected your daily life?* I do lose my cool but in my defence I am tired, very I mean quarter to three, quarter past three, I am awake and I don't, I only dose from about quarter past three 'til the alarm goes off at about half past six and then I'm up, make Rod's tea and take it up to him and I'm on the go 'til can be half past nine half past ten at night, I barely sit down do I Rod? really I might watch the six o clock news but normally Rod's away Mondays and Fridays, he goes to the White Lodge at Coderidge, respite no day services, he doesn't like it but the taxi comes and picks him up and of course Rod has respite at Nightingale lodge it's usually every ten weeks for one week, it has six days but there's been increased because I've been going downhill a little bit health wise and um at the last conference my son said oh my mum's getting so tired and I said oh I'm alright and he said you're not mum and I said well when you're working 14, 15 hours a day without a break I eat almost on the hoof you know a piece of toast when I'm doing his and obviously it's shown and I	Can lose cool but is apologetic & defensive in tone – why? Caring is tiring – full days no breaks In poor health and downhill 'working' demanding role

is suggestion of counselling
'I'm fine' sudden on
I can't relax
everything through mind - prevents sleep
It's awful - repeated emphasis
Keep the button [illegible] the time
like a young child
needs to keep busy
got on so well - social
others don't understand what helps me
gives me a focus
keeps busy
stopped due to Rod's stroke
loved work
Daily life focused on Rod
Past - hobbies go out
Loneliness people backed off
daughter - heartbreaking
Not a life you'd choose
wedding vows
this is my role, he'd look after me if situation reversed
life without him wouldn't be life
Good companions

went down to One Community and um they suggested I need counselling and I said I don't need counselling for goodness sake I'm alright um yes so I've had aromatherapy a fortnight ago, that was quite nice but I can't, I wish I could but I can't relax I twitch all the time so I said well give it after Christmas because I agreed that I will go after Christmas and have counselling ... I think the sleep pattern is my worst but I will not, I won't take sleeping tablets but I'm going through everything when I'm awake, I'm going through what I've done, what I've got to do and all this it's awful, it's awful and uh so that is something I've got to try and address if I can I'm constantly tired but is that because of the circumstances here or is it because my health isn't quite back to normal you know ... you've to be on the button all the time really haven't you it's like when you have a young child a two year old [laughs]

[...]

and yet I'm a doer you see I've always got to have something, I mean this memory club has done wonders for me, started this up and oh when you think we only started with just a few people just for coffee after our carers' club we all got on so well and we just used to meet there for coffee and next year we're having the big hall but you see they say well you're doing much, you're doing too much you should all do this, no I'm not it takes a lot of my time a lot of writing and phoning and things like that but um it's given me a focus I know it's the same sort of thing looking after people and but it's given me a focus because to be quite honest I'm sure if Rod hadn't had his stroke, because I retired at 65 and three weeks into retirement the phone went, Joan nobody's filled your post can you help us out I said well I'll have to go on the agency. I joined the agency and went back into the same position as I had on the same ward, a lot more money I said put me down a grade they said no it's only for a few weeks and I was there until I was 72 and um I woke up at three o'clock in the morning and Rod was having another stroke so from that day I stopped, I stopped overnight and I swear that if that hadn't happened I would still be on my ward because I loved it

[....]

How has it affected it um well I think my daily life is wholly focused on Rod I think now I used to have hobbies used to go out I don't now, I think it's affected me by the loneliness of it because we used to have people who would call, we don't have anyone now they've backed off um I don't think they know how to handle the situation um my daughter can't handle it at all um and that I find heartbreaking to be quite honest um it it's just different it's not if I might say it's not a life one would choose you know um but for me I always sort of go through my wedding vows and in sickness and in health and I'm pretty certain if it was the other way round Rod would look after me um so I feel this is my role you know um I have met people who say oh you're foolish you know you could have more life but life without Rod wouldn't be life for me um at all we're still good companions, we still watch the television together we make ourselves watch the weakest link and see if we can answer

Always sees self as fine and finally explaining things she's not
Inability to relax to sleep, to get away, carer role has no break even in rest
emphasis on word 'awful'
like looking after a young child
Having a focus, a distraction helps
others don't understand the value of this
Personality - always loved work
Life now revolves around Rod, hobbies etc have fallen by the wayside
Social - loneliness, people back off even family
Not what I would choose but it's a part of marriage role
Marriage has evolved + changed now

Appendix N

THE ZARIT BURDEN INTERVIEW (ZBI)

ease circle the response the est describes how you feel. Never	Rarely	Sometimes	Quite Frequently	Nearly Always	**Score**
Do you feel that your relative ks for more help than he/she needs?	0	1	2	3	4
Do you feel that because of e time you spend with your elative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed ween caring for your relative and trying to meet other sponsibilities for your family or work?	0	1	2	3	4
. Do you feel embarrassed er your relative's behaviour?	0	1	2	3	4
Do you feel angry when you are around your relative?	0	1	2	3	4
Do you feel that your relative currently affects our lationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the ture holds for your relative?	0	1	2	3	4
Do you feel your relative is dependent on you?	0	1	2	3	4
Do you feel strained when u are around your relative?	0	1	2	3	4
Do you feel your health has suffered because of your olvement with your relative?	0	1	2	3	4
. Do you feel that you don't ve as much privacy as you vould like because of your relative?	0	1	2	3	4
Do you feel that your social e has suffered because you re caring for your relative?	0	1	2	3	4
. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4

Appendix O

Depression, Anxiety and Stress Scales (DASS)

DASS

Name:

Date:

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found myself getting upset by quite trivial things	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I just couldn't seem to get going	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I had a feeling of shakiness (eg, legs going to give way)	0	1	2	3
8	I found it difficult to relax	0	1	2	3
9	I found myself in situations that made me so anxious I was most relieved when they ended	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting upset rather easily	0	1	2	3
12	I felt that I was using a lot of nervous energy	0	1	2	3
13	I felt sad and depressed	0	1	2	3
14	I found myself getting impatient when I was delayed in any way (eg, lifts, traffic lights, being kept waiting)	0	1	2	3
15	I had a feeling of faintness	0	1	2	3
16	I felt that I had lost interest in just about everything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3

19	I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life wasn't worthwhile	0	1	2	3

1	I found myself getting upset by quite trivial things	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I just couldn't seem to get going	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I had a feeling of shakiness (eg, legs going to give way)	0	1	2	3
8	I found it difficult to relax	0	1	2	3
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16	I felt that I had lost interest in just about everything	0	1	2	3
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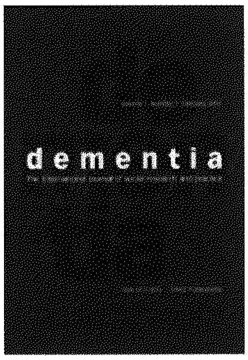
18	I felt that I was rather touchy	0	1	2	3
19	I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life wasn't worthwhile	0	1	2	3

Appendix P

Guidelines for authors for Dementia



Dementia

The International Journal of Social Research and Practice

Editors: John Keady University of Manchester, UK

Notes for Contributors

1. The aim of the journal is to publish original research or original contributions to the existing literature on social research and dementia. When submitting papers for consideration, please attach a letter confirming that all authors have agreed to the submission, and that the article is not currently being considered for publication by any other paper or electronic journal.

2. Each paper submitted, if considered suitable by the Editors, will be refereed by at least two anonymous referees, and the Editors may recommend revision and re-submission.

3. *Length of papers.* Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Please also supply an abstract of 100-150 words, and up to five keywords arranged in alphabetical order.

4. When submitting a paper for consideration, our preferred method of receipt is as an electronic version and as a Microsoft Word document. This should be sent via email attachment to one of the Editors outlined in Note 18, together with a separate covering letter. If this is not practicable, please supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations). Rejected papers will not be returned to authors.

5. Your typescript (written in English) needs to be typed using double spacing on one side only of white Aor US standard size paper, with generous left and right-hand margins.

6. Your title page should give: one first name as well as the surname and any initials for each author; a maximum of four degrees/qualifications for each author and the current relevant appointment only; authors' accurate postal addresses; daytime telephone numbers, and fax and email numbers.

7. *Quotations.* Lengthy quotations (over 40 words) should be displayed and indented in the text.

8. American or UK spellings may be used. Please use single quotation marks. Dates should be in the form '9 May 2000'. Delete full stops/periods from 'USA' and other such abbreviations.

9. If the paper is accepted for publication, a copy of the final version will be required as either an email attached Microsoft Word document, or on disk in a PC-compatible format. The author is responsible for ensuring that the final version of the article matches exactly the one required by the Editors.

10. *Tables.* You should present tables in your manuscript typed double-spaced on separate sheets and containing only horizontal rules. Each table needs a short descriptive title above it. Column headings should clearly define the data presented. If necessary, suitably identified footnotes should be included below. Take care to include all the units of measurement. The table needs to be cited in the text.

11. *Figures.* Line drawings should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, 800 dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, 300 dpi.

12. *References in the text* should be presented in American Psychological Association (APA) style, i.e. the author's name and year of publication in brackets, together with the page numbers, e.g. 'As Kitwood (1997, pp 40-41.) has observed', or, in a more general reference: 'Kitwood (1997) appears to be saying ...'

13. *Reference list.* The references should be listed alphabetically in full at the end of the paper, typed double-spaced for ease of editing, in the following style:

Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, 17(4), 597-607.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.