

CARING FOR A SPOUSE WITH DEMENTIA:
A LITERATURE REVIEW AND EXPLORATORY STUDY OF
CARERS' EXPERIENCE OF THEIR MARITAL RELATIONSHIP

DECLARATION

These papers have not been submitted either whole or in part for any other degree or to any other institution.

STRUCTURE AND WORD COUNT

This thesis (Literature Review and Research Report) has been prepared in accordance with the Guidance For Contributors to The Journal of Aging and Mental Health. A copy of this guidance together with the letter of approval of the specified journal from the Research Tutor can be found in Appendix 1.

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**CARING FOR A HUSBAND OR WIFE WITH DEMENTIA: A LITERATURE
REVIEW AND EXPLORATORY STUDY OF CARERS' EXPERIENCE OF
THEIR MARITAL RELATIONSHIP**

THESIS ABSTRACT

This thesis comprises three main sections. The first is a literature review on the influence of marital relationship on the experience of spouse carers of people with dementia. Due to methodological weaknesses findings need to be interpreted with caution, however, the research suggests that positive pre-morbid and concurrent relationships are indicative of greater wellbeing in spouse carers, and also that dementia impacts negatively on marital relationship. Implications for clinical practice and ideas for future research are explored.

Section Two is a report on a study exploring spouse carers' experience of their marital relationship whilst caring for a husband or wife with severe dementia. Ten spouse carers (six wives and four husbands) of people suffering from severe dementia participated in a semi-structured interview which was transcribed and analysed in accordance with Interpretative Phenomenological Analysis (IPA) methodology. Five interrelated processes with 19 sub-themes were identified; Establishing connections and forming a lasting relationship, Experiencing dementia as a threat to the relationship, Attempting to maintain the existence of a relationship, Desire to care and Experiencing the impact of caring on wellbeing. Implications for clinical practice and further research are discussed.

The third section provides a critical appraisal of the research process and includes an exposition of key lessons learnt, future Continuing Professional Development needs and personal reflections on future functioning as a researcher within the role of a Clinical Psychologist.

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SECTION ONE

THE INFLUENCE OF MARITAL RELATIONSHIP ON THE EXPERIENCE OF

SPOUSE CARERS OF PEOPLE WITH DEMENTIA –

A REVIEW OF THE LITERATURE

**THE INFLUENCE OF MARITAL RELATIONSHIP ON THE EXPERIENCE OF
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**THE INFLUENCE OF MARITAL RELATIONSHIP ON THE EXPERIENCE OF
SPOUSE CARERS OF PEOPLE WITH DEMENTIA –
A REVIEW OF THE LITERATURE**

ABSTRACT

Purpose:

This review evaluates the literature on the influences of the marital relationship on the experiences of spouse carers of people with dementia.

Method:

Papers were sourced through electronic databases (Psychlit, Medline, CINAHL and Embase 1980-2007) and supplemented by traced citations. Only papers in English and where analysis allowed results for spouse carers to be separately drawn from the study were included.

The review is structured into a) important contextual factors b) the effects of the pre-morbid relationship, c) the effects of concurrent relationship d) the impact of dementia on the relationship, and e) conclusions, including implications for clinical practice and future research ideas.

Results:

A number of methodological weaknesses were evident within the studies and therefore findings need to be interpreted with caution. However, the research suggests that positive pre-morbid and concurrent relationships are indicative of greater wellbeing in spouse carers, and also that dementia has a negative impact on marital relationships.

Conclusions:

Further research is required in order to consolidate findings and to expand the knowledge base. Clinical practice should take into account past and present marital relationship and aim to support carers in maintaining (or developing) a close relationship during caring.

THE INFLUENCE OF MARITAL RELATIONSHIP ON THE EXPERIENCE OF
SPOUSE CARERS OF PEOPLE WITH DEMENTIA –
A REVIEW OF THE LITERATURE

INTRODUCTION

Background and Aim of the Review:

The role of informal carers ('people who are looking after or providing some regular service for a sick or handicapped or elderly person living in their own home or another household' Office of Population, Censuses and Statistics, 1988 p.444) in supporting individuals suffering from dementia has been acknowledged for several decades. However, despite recent attempts to scope the prevalence and costs of dementia in the U.K. (Alzheimer's Society 2007) there is still a gap in knowledge about the nature of the relationship or bond between the person with dementia (PWD) and their informal carer/s, although it has been estimated that up to two thirds of all carers for individuals suffering from dementia are spouse carers (Brodaty & Green, 2000).

This lack of clarity about demographic profile of carers may be due to the fact that dementia is often insidious in onset, may be confused with the effects of normal aging, and is still regarded as a stigmatising illness (Jolley & Benbow, 2000). It is also likely that some spouses perceive themselves as fulfilling marital duties rather than fulfilling a carer's role (Cayton, 2002).

Over the past 30 years there has been a considerable amount of research focussing predominantly on negative consequences of caring for somebody with a dementia in terms of the impact on carers' physical and mental health status (for a review see Pickard, 2004, Vitaliano et. al., 2003, and Cuijpers, 2005).

Intuitively the type of bond or relationship between sufferer and carer could be expected to be one of the main influencing factors in the experience of the carer, however surprisingly most studies appearing in the literature have used mixed samples, failing to employ deliberate sampling techniques to target particular relationship types or having sufficient sample sizes to separate out relationship as part of the analysis.

The aim of this paper is to provide an evaluative review of the literature on the influence of marital relationship on spouse carers of a partner with dementia. In order to provide adequate background context before the review a brief summary of the current knowledge on epidemiology, the profile of carers and the factors which affect the experiences of carers of dementia sufferers is provided.

Context for the Review

Definition and Epidemiology of Dementia

The word dementia is derived from the Latin 'demens' which means 'without mind' and has been used to indicate lack of capacity or competence to manage one's own affairs since the early eighteenth century. From the early

nineteenth century the term dementia has been slowly evolving in medicine from the non-specific notion of an acquired organic brain syndrome to the more specific and operationalised definitions seen today (McKeith & Fairbairn, 2001).

For example according to the International Classification of Diseases version 10 (ICD-10), dementia is described as:

'a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.'
(World Health Organisation, 1992 p.45)

Over the past 20 – 25 years, definitions have become more precise about the clinical features which comprise dementia and a number of causes have been identified i.e. neurodegenerative (e.g. Alzheimer's disease, Dementia with Lewy Bodies, Frontal or Fronto-temporal dementias), vascular (e.g. infarction, Binswanger encephalopathy), endocrine disorders (e.g. thyroid disease), vitamin deficiencies (e.g. Vitamin B12), systemic diseases (anaemia), neurological disorders e.g. Normal Pressure Hydrocephalus) and infection (e.g. Syphilis and HIV) (Eastley & Wilcock, 2000).

According to a recent survey by the Alzheimer's Society in the U.K.

(Alzheimer's Society, 2007), the most common dementias are

neurodegenerative and vascular dementias and it is estimated that 1.1% of the

entire UK population are affected with prevalence doubling with every 5 year increase in age ranging from 1.3% in the 65-69 years olds to 32.5 % in the 95+ year olds. Young onset dementia (onset before 65 years of age) is comparatively rare with 2.2 % of all people suffering from dementia in the UK. The most common form of late onset (i.e. after 65 years of age) dementia is Alzheimer's disease (62%) followed by vascular dementia and mixed dementias accounting for nearly a third (27%) of all cases.

In the early stages of a progressive dementia, sufferers may be able to live independently but as impairment in a number of cognitive domains becomes more significant, increasing support with a variety of activities will be required. In the advanced stage individuals will be incapable of managing their own financial and legal affairs and be typically dependent on others to meet their very basic needs. Language may be reduced to simple phrases or words, mobility becomes compromised and support with eating and toileting is usually necessary (Forstl, 2000). The estimated median survival time for individuals with Alzheimer's disease is approximately 7 years compared with approximately 4 years for those with vascular dementia (Fitzpatrick et. al., 2005).

Profile of Informal Care

The majority of individuals suffering from dementia live in private households in the community rather than institutional care. In the early stages of a dementia a significant proportion of people are able to live alone in the community and may be supported by friends, and/or relatives (Alzheimer's Disease Society, 1994), however as the disease progresses to the moderate and severe stages

the majority of people living in the community are cared for by somebody living in the same home (Schneider et. al.,1993). The proportion of those with dementia living within care homes rises steadily with age from 26.6% of those aged 65-74 to 60.9% of those aged 90 years and over (Alzheimer's Society, 2007).

The mainstay of dementia care in the U.K. is therefore care which is provided by informal carers i.e. family and friends and two studies suggest that as much as 70% or more of total home care costs are accounted for by informal care (Rice, et. al.,1993, Stommel, et. al., 1994). Perhaps not surprisingly there are cultural differences regarding which family members take on care. In Australia, the USA and the UK it is estimated that between one and two-thirds of carers are spouses, and around 75% of these wife carers although figures vary depending upon county surveyed and sampling techniques used, whereas in Asian countries such as China and Hong Kong, adult children are more often the carers than spouses (Brodaty and Green, 2000).

The Impact of Caring for a Person with Dementia (PWD)

Zarit and colleagues were among the first researchers who highlighted the burden of providing care to a relative with dementia (Zarit et.al.,1980).

Following this study there has been an exponential growth of research on care-giving. Whilst there have been some attempts to explore positive gains associated with providing care, for example feeling appreciated by the person receiving care and feeling good about the quality of the care provided (for a review see Krammer, 1997), research has focussed mainly on the negative

effects of providing care in particular the effects on carers' mental and physical health.

In respect to mental health two review studies have been published in recent years. Schulz et. al.(1995), reviewed the literature in relation to carers of people with dementia and found that almost without exception, studies reported higher levels of depressive symptomatology among carers with one third to a half of all carers suffering from symptoms of depression. In addition studies using diagnostic interviews reported a higher incidence of clinical depression and anxiety. Many of the studies recruited study participants seeking support from health or social care organisations and thereby were considered to have possibly incurred sample bias, however, some notable exceptions within the review using population based samples (e.g. Gaftrom et. al.,1992) and control groups (e.g. Baumgarten et. al. ,1992) still yielded good quality evidence for elevated morbidity in carers.

Cuipers' (2005) more recent review of UK and USA studies examining the prevalence of depressive disorders in carers of PWD, confirmed that the prevalence and incidence of depressive disorders are increased in carers and mirror the prevalence rates for depression in the general population in terms of gender differences, with a higher prevalence rate for women. Unfortunately, the number of studies comparing types of carers in respect to their relationship with the sufferer was small and therefore no definite conclusions could be drawn in respect to whether this factor was significant. However in line with the demonstrated higher levels of depression in female carers, Beeson et. al. (2000), and Alsphaugh et. al. (1999) found that care giving wives more likely to

be depressed than care giving husbands. There is also some evidence to suggest the demands of caring are experienced differently by husbands and wives, with a tendency for husbands to concentrate more on problem solving and the provision of concrete or practical care giving tasks and to minimise their emotional reactions to caring (McFarland & Sanders, 1999).

Another study by Russo et. al. (1995) investigating the effects of pre-existing psychiatric disorders in spouse carers found that those with a history of psychiatric disorder prior to their spouse being given a diagnosis of dementia were more likely to experience a recurrence after the onset of the dementia than control participants with no history of psychiatric illness.

It has also been suggested that the depression typically identified in carers of PWD may be best understood as a form of anticipatory grief (Fittings et. al., 1986 and Schulz et. al., 1990,) and therefore a section on the relevance of this concept for carers is included within the section on the effects of dementia on the marital relationship (page 26).

With regard to carers' physical health, Vitaliano et. al., (2003) conducted a meta-analysis of 23 published studies over a 38 year period investigating the physical health of carers compared to demographically similar non-carers. A number of different categories of measures of physiological functioning have been used in these studies including stress hormones and neurotransmitters (including both Cortisol and Adrenocorticotrophic hormone which have been linked to depression), immunologic, cardiovascular and metabolic functioning. They established good evidence that carers had slightly increased risk factors

for illness including lower levels of antibody responses and higher stress hormones than non-carers. Thus whilst it is not possible to determine whether caring causes illness, there is evidence that caring influences the risk factors for illness and also potentially affective disturbance.

Factors Related to the Experience of Carers of People with Dementia (PWD)

A number of factors including demographic variables, carer and sufferer characteristics have been investigated as potentially related to the genesis of depression, stress and burden in carers of PWD. For example, there appears to be an association between available informal support and lower distress but the causal linkage remains unclear (Brodaty & Green, 2000). In addition, racial and cultural beliefs about dementia affect how families both respond to the challenges of caring and the interventions designed to support carers Haley et.al. (1998).

The association between cognitive impairment and sense of burden and reported stress remains unclear with conflicting results being reported. Some studies document a weak association of objective measures of sufferers' functional status and carer burden and depression (Kiecolt-Glaser et. al. 1991, Russo et. al. 1995) whereas others report a stronger relationship (Baumgarten et. al., 1992 and Gallant & Connell, 1997). One of the problems encountered by these studies is that PWD who have declined functionally, are more likely to exhibit behavioural disturbances, and despite differences in populations, and assessment and outcome measures, a consistent association between behaviour disturbances in the sufferer and negative psychological symptoms in the carer emerges e.g. Black & Almeida (2004) Brodaty & Hadzi-Palovic

(1990) and Cohen et. al. (1997). However, additional recent research has found evidence to suggest that carers' coping style, in particular 'escape-avoidance' coping (e.g. avoiding people, wishing the situation would go away) partially mediates this association (Mausbach et.al., 2006) and furthermore, de Vught, (2005) suggests that it is carers' response to behavioural difficulties manifested in the sufferer rather than the behavioural difficulties themselves which determines nursing home placement.

With the exception of a few notable examples (e.g. Poulshock & Deimling, 1984, Pearlin et. al., 1990 and Williamson & Shaffer, 2001), research on factors related to the experience of carers of PWD has focussed on establishing associations and correlations between factors rather than investigate causal pathways. This may in part account for why interventions with family carers of people with dementia appear to have limited efficacy (Carradice et. al., 2003).

It is perhaps surprising, given the evidenced negative impact on many carers' mental and physical health that carers often continue in their caring role. An often overlooked factor which may in part account for this desire to continue caring is the relationship between sufferer and carer i.e. how much the person and the relationship with the person is affectively valued by the caregiver, e.g. feelings of emotional closeness, having positive sentiment towards them and having shared values and beliefs (Lawrence et. al., 1998).

Pearlin et. al. (1990) proposed that the background and context of caring (including pre-morbid relationship) leads to primary stressors, secondary role

strains and secondary intra-psychic strains. Within this model, relationship quality is viewed not only as a product of the stressors, but also as providing a 'particular lens through which stressors are interpreted or appraised', Lawrence et.al., (1998 p.157). Thus, relationships can either play a mediating or moderating role between the various demands or strains generated within the care giving situation and the impact of these on the carer. In the mediating role as stressors increase the quality the relationship suffers. Relational deprivation or negative reappraisal of the marital relationship can develop from carers feeling deprived of a relationship with a significant other and loss of an affectionate exchange as the dementia progresses, which in turn affects the quality of life of carers and continuity and quality of care for the sufferers. Within the moderator role the relationship has the potential to modify the impact of the stressors i.e. if the carer feels emotionally close to a sufferer they may appraise the situation more positively and thereby be buffered from the negative consequences of caring. Thus a carer with a strong positive relationship may feel less burdened and stressed relative to somebody with a poor relationship despite similar care giving situations and comparable objective stressors. However, as noted by Pruchno & Resch (1989), it is likely that both processes occur simultaneously i.e. the quality of the relationship will affect the carer's perception of stressors and thus potentially buffer the carer from negative consequences, and the quality of the relationship may also be altered by the presence of stressors which will increase negative consequences for the carer.

This paper now reviews and critically evaluates the scientific published literature on the influence of marital relationship on the experience of spouse carers of PWD.

METHOD

Electronic reference searches were carried out for the period 1980 – 2007 using several bibliographical databases including Psychlit, Medline, CINAHL and Embase. Terms for dementia (dementia, senile dementia, Alzheimer's disease, multi-infarct, and vascular dementia) were combined initially with terms for carer (carer, care-giver). This search was then refined by using terms for spouses (e.g. spouses, partners, husband*, wives, wife, and couples) and followed by the term 'relationship'. Additional sources were traced through citations from those articles identified through the electronic search.

Research was included if it was reported in English and contained sufficient sample sizes of spouses for data analysis to be reported for this sub-group of carers, and excluded if it was written in a different language and if results for spouses and other kinds of carers (e.g. adult children carers) were combined. Approximately 45 papers were identified, and 2 excluded on the basis of combined samples.

The following structure was adopted to assist the review; the influence of pre-morbid marital relationship on the experiences of carers, the effects of the concurrent marital relationship on the experiences of carers, the effects of dementia on the marital relationship from the carer's perspective, conclusions,

implications for clinical practice and finally, recommendations for future research.

RESULTS

The Influence of Pre-morbid Marital Relationship on the Experiences of Carers Of People with Dementia (PWD)

Several studies have investigated the influence of pre-morbid marital relationship on the experience of spouse carers. Morris et al. (1988), using a specifically developed Marital Intimacy Scale based on the operational definition of intimacy provided by Waring et. al. (1980) comprising 24 statements covering 8 domains i.e. affection, cohesion, expressiveness, compatibility, conflict resolution, sexuality, autonomy and identity, found that those carers with lower pre-morbid levels of marital intimacy were more at risk of depression. However these results need to be interpreted with caution as ratings of pre-morbid marital intimacy were completed retrospectively and may have been influenced by the respondents' emotional wellbeing at the time of the study. In addition depression was measured by the Beck Depression Inventory (BDI) which includes items related to physiological effects of low mood which may be contaminated by co-morbidities often affecting older people.

A further three studies using different but again retrospective measures of marital intimacy, and different measures of depression (Krammer, 1993 and Williamson & Shaffer, 2001 using the Centre for Epidemiologic Studies Depression Scale – CED-S [Radloff 1977] and Ballard et. al., 1995 using the

Research Diagnostic Criteria) confirmed these findings. The study by Krammer (1993) which sampled only wife carers, also suggested poorer pre-morbid relationship is associated with less satisfaction with care-giving and lower quality of life, and noted that those who had been married only once reported significantly higher levels of quality of life, were more satisfied with their social involvement and reported better health than those who were in their second or subsequent marriage.

A more recent study by Williamson & Shaffer (2001) used a sample of spouse carers of which fifty percent were caring for a PWD. Results indicated that regardless of how much care was provided and irrespective of whether the care recipient was suffering from dementia, those carers who perceived their pre-illness relationship as highly communal (i.e. characterised by mutual responsiveness to each other's needs) reported less symptoms of depression and engaged in fewer potentially harmful behaviours towards the sufferer. However, there was evidence that carers of dementia sufferers received fewer current relationship rewards and fewer current relationship rewards was associated with greater levels of depressive symptomatology being reported. It was suggested that in historically communal relationships, providing care translated to continuing to meet the other's needs as they arose, knowing that their partner would have done the same if the need had arisen. Williamson & Shaffer (1998) suggest that although previously communal spouses are saddened by watching their husband or wife decline and by losses in the rewarding aspects of their previous relationship, they are more likely to feel good after having helped their partners and more likely to attribute their distress to the illness condition rather than their dependant. Conversely, those

spouses in less communal marriages are thought more likely to provide care out of a sense of duty or obligation and more likely to blame their distress on the sufferer than the situational aspects of his/her illness.

Unfortunately, in all these studies ratings of pre-morbid relationship have been completed retrospectively. Therefore results needed to be interpreted with caution as it is possible that carer dysphoria may affect responses. In addition, O'Rourke & Wenaus (1998) has found some evidence to suggest that spouses of PWD may evoke a response bias in terms of discounting negative beliefs about their marriage (appraising their marriage and spouse inordinately positively), as a coping strategy to reduce the degree to which the stressors incurred through caring are perceived as taxing their resources.

Complimenting these quantitative studies are two examples of qualitative research. Siriopolos et.al. (1999), explored the experiences of husbands caring for their wives and identified quality of the previous relationship as significant in carers' desire to continue caring. Morgan & Laing (1991) using Grounded Theory, explored the impact of a diagnosis of Alzheimer's disease from the perspective of nine spouse carers in the first six months following diagnosis. They found that the quality of the previous relationship was the crucial variable which determined whether the carers' experience was predominantly characterised by grief or by role strain. Those with a close pre-morbid relationship described how they were grieving for the valued positive aspects of their relationship with their spouse, and wanted to continue caring in order to provide some continuity in their relationship. They attempted to 'see the world from the spouses' eyes' (p383) and tended not to view their spouses'

actions as being deliberately hurtful or difficult. They also reported gratification from their caring role. The role strain group in contrast reported poorer pre-morbid relationships and believed it was their duty to care. They reported less gratification from this role, less tolerance of difficult behaviours, and greater subjective burden. However, this research again relied on retrospective accounts and did not take into account either the affect status of the carers' or the level of disability of the spouse both of which may have influenced the carers' experience.

In summary, research suggests that it is important to remember that caring has a historical context in which the carers' relationship with the PWD is significant. Those carers who during caring perceive their marital relationship prior to the onset of dementia as less close, have a higher risk of depression and are more likely to experience less satisfaction and rewards during caring. Further longitudinal research and research which addresses the potential response bias associated with depression in respondents is required in order to evaluate whether poor pre-morbid relationship is de facto a risk factor for depression in spouse carers of PWD. In addition qualitative research exploring the subjective meaning and impact of pre-morbid relationships from both the carer and care recipient perspectives would be helpful in illuminating the carer and PWD experience.

The Effects of the Concurrent Marital Relationship on the Experiences of Spouse Carers of People with Dementia

Another vein of research is concerned with how marital functioning during caring influences the experiences of spouse carers of PWD. For example,

Rankin et.al. (2001), using convenience samples of those couples seeking help, demonstrated that spouse carers of PWD reporting low levels of marital cohesion and satisfaction experience significantly more depressive symptoms.

This study measured depression with the CED-S and current marital functioning with the Family Adaptability and Cohesion Scale- Couples version (Olson et. al., 1985) and The Family Satisfaction Scale (Olson & Wilson 1985) in addition to care taking involvement, functional, behaviour and psychiatric status of the sufferer. Results suggested that changes in the cognitive, behavioural and functional status of the PWD were associated with the level of depression the carers experienced, but also that current marital functioning was significantly and independently associated with the carers' mental health. It was also noted that wives were significantly more likely to suffer from depression than husbands and that losses associated with emotional rather than instrumental support were more influential in accounting for the depression.

This led the authors to propose that as the sufferer's cognitive status deteriorates and erodes their capacity to maintain intimate relationships, the function of the marital relationship in maintaining the carer's sense of self is compromised. This explanation is supported by an earlier study by Skaff & Pearlin (1992), which demonstrated that greater depressive symptomatology is associated with engulfment in the caregiver role and a loss of identity or self concept as result of erosion of 'couple identity' in a previously intimate marital relationship.

Similarly, a study by Lewis et.al. (2005), used qualitative data to classify spouse carers of PWD into 4 self expressed perspectives and quantitative measures for the assessment of carer distress. Carers who defined their experiences in the context of the past, present and future relationship with their spouse and centering on the continued bond or connection i.e. were 'Relational' reported less depression. 'Instrumental' spouses whose experience was dominated by the additional tasks and burdens associated with caring, 'Reactive' spouses whose experiences focused on changes in PWD, and 'Role Acquiring' spouses whose experience was dominated by the expansion of the self through taking on roles were more likely to report depression and also scored less positive responses and outcomes on a range of measures e.g. burden, role captivity, caregiver competence and positive aspects of care-giving.

However, this research used carers who were often less than two years into the caring role and further follow up research would be required to ascertain whether these perspectives and differences were stable over time and what impact they have over the care-giving trajectory. For example, research by Wright (1994), suggests that marital interactions may in part determine whether residential placement is sought for the sufferer. More specifically, those spouses who report higher levels of positive spousal interactions are more likely to continue in the caring role whereas those who perceive their current marital functioning to be unhappy are more likely to seek institutional care for the PWD.

However, offering some contrast to this body of research which seems to indicate that close marital relationships are less likely to lead to depressive symptoms in the carers, is one of the few longitudinal studies appearing in the literature. This study by Tower et.al. (1997), explored the extent to which marital closeness moderates the impact on the wellbeing of the carer when caring for a spouse with cognitive impairment. This study used a relatively large community sample (317 couples) thereby eliminating the bias encountered when sampling subjects from secondary or tertiary health or social care agencies. Measures included a screening tool for the detection of dementia in community samples (the Short Portable Mental Status Questionnaire Pfeiffer, 1975), the CED-S for depression and a measure of couple closeness constructed by the authors. This latter measure categorized carers into 3 groups according to whether they and their spouses spontaneously named the other when asked who was a confidante or source of social support, (mutually close, mutually distant and those where a feeling of closeness was indicated by only one of the couple).

Findings suggest that husbands of severely cognitively impaired wives in mutually close marriages were significantly more likely to report depressive symptomatology than those who were not in mutually close relationships, and this result was stable over time. Interestingly whilst wives on the whole tended to report higher levels of depression than husbands (apart from those husbands in mutually close marriages) this effect was not demonstrated for wife carers. Furthermore, if a wife had been severely impaired and died within the 3 years the husband became less depressed after her death whereas if the

wife was unimpaired and died the husband was more depressed following bereavement.

These apparent gender differences are difficult to interpret and conflict with earlier research which has consistently found that close marital relationships during caring are generally predictive of better mental health outcomes for the carers. A number of hypotheses as to why these results may have been found can be generated. For example, whilst one of the potential strengths of the research was the use of a community rather than a convenience sample this may have resulted in a different subsection of male carers (and wife sufferers) taking part in the study which would not normally seek help from support agencies used to recruit research participants. These couples may be more socially isolated and be over-reliant on each other as a confidante or a source of social support. (For instance it may be that husbands in close marriages perceive their wives as a key resource in terms of social support, shared activities etc and are distressed when access to the resource is threatened. Similarly it may be that the wife who may typically have a more extended circle of intimate relationships becomes more dependent upon her husband as her cognitive functioning declines.) In addition it is possible that the choice of measure for marital closeness, with its emphasis on social support influenced the results differently, and finally, it is possible that cognitive impairment had affected baseline marital closeness.

In summary this research suggests that concurrent marital functioning is associated with carers' emotional wellbeing during caring. For those carers recruited through support agencies, on the whole more positive relationships

(especially where the relational aspects are retained) are indicative of better mental health. For community samples this finding is more equivocal and it is possible that there are differential gender effects. However, causal pathways still remain unclear and further longitudinal studies, studies controlling for gender and the potential bias of depressed affect plus research using community samples are required. In addition, further qualitative research exploring the experience of the concurrent marital relationship from both the carers' and PWD's perspectives could further our understanding of its impact on carers' and sufferers' wellbeing.

The Effects of Dementia on the Marital Relationship.

The largest body of literature (including quantitative, qualitative, single case studies and texts reporting professional opinion and indeed lay texts) is in relation to the effects of dementia upon the marital relationship. Eloneimi-Sulkava et. al. (2002), employed semi-structured telephone interviews to elicit information on the general atmosphere of marriage, happiness, relations (the degree to which there was equal companionship rather than a dominant partner) and sexual behaviour in couples where one spouse was suffering from dementia both before the onset of dementia and during caring.

Results indicated that statistically significant declines in overall happiness, equal relations and sexual expression (with the exception of a small number of husbands who became hypersexual) occurred following dementia, whilst there was no significant change in the overall atmosphere of the marriage. These findings however do need to be interpreted with caution due to the small sample size (n=42), a reliance on retrospective measures and the absence of

a comparison group or adequate controls for the effects on co-morbidities and medication on the expression of sexual behaviour. Of interest however is the replication of the finding relating to sexual behaviour in two additional studies, Ballard et. al (1997) and Wright (1998).

A second study by Wright (1991) compared healthy married couples with couples in which one spouse was a PWD using open-ended questions relating to marital quality and coping and the Dyadic (Marital) Adjustment Rating Scale (Spanier & Thompson, 1982). This latter measure consists of four subscales; consensus, tension, cohesion and affection. Results indicated that those couples affected by dementia were incongruent in their perception of tension and agreement over sexual issues and caregivers differed significantly from well group spouses on companionship and marital quality, rating these lower.

A more recent study by Beeson (2003), using a sample of carers enrolled in a dementia research centre and a non-care-giving control group supported this finding in respect to companionship, identifying that spouses caring for PWD report significantly more loneliness and depression than non-care-giving spouses. Interestingly whilst the loss of a reciprocal relationship and the loss of self resulting from the caring role was experienced similarly by husbands and wives, greater feelings of loneliness and depression were only reported in wives, supporting earlier research that found that the demands of caring are experienced differently by husbands and wives (e.g. Rankin, 2001).

Interestingly, de Vught et.al. (2003) also showed that there are differential effects of behavioural disturbance on the quality of the relationship with

passive rather than excessive behaviours having the greatest negative impact on the relationship, and it is hypothesised that this is because passive behaviours in particular could diminish joint activities and companionship.

There is however some evidence (in the form of two recent single case studies using qualitative methodologies to explore a couple's experience of the marital relationship when one spouse has been diagnosed with dementia) to suggest that companionship or 'working together' may not be rescinded easily or willingly by some couples. In both studies the PWD contributed interview data and it therefore is assumed that this research is conducted in the early stages of dementia. Hellstrom et. al. (2005), interviewed the carer and spouse with dementia separately but simultaneously eight times over an 18 month period and found that both partners were seeking to maintain the involvement of the spouse with dementia. Daniels et.al. (2007), interviewing the couple together found 4 emergent themes; perspectives about and preparation for the future, (e.g. how they considered themselves to have a lifelong commitment to each other and how they perceived the history of their relationship significantly influencing how they were going to approach and plan for the future), family influences and social support (e.g. the role the family played in the couple's life together and the support they received from their social network), life evaluation (e.g. their evaluation of the different aspects of their life together such as employment, living situation, finances and compatibility over their life course together including present day), and experiences with Alzheimer's (e.g. role changes, the couple's understanding of the disease and the acknowledgement of the influence of Alzheimer's disease on their relationship). Obviously these are single cases, and represent experiences at

the beginning of the illness and thereby the findings cannot be generalised, nevertheless, they add an interesting insight into the perspectives not only of carers but also of the sufferers themselves and further research adopting similar methodologies are required to explore these findings further.

Another body of literature has suggested that carers looking after a PWD may experience dysphoria associated with anticipatory grief (Walker & Pomeroy, 1996), i.e. the grief responses (mourning and detachment) in people who were not yet bereaved but who had been separated from their loved one (Lindemann (1944) and Sweeting & Gilhooley 1990)

A longitudinal study by Collins et. al., (1993), followed largely spouse carers before and after bereavement. Using content analysis of responses to open ended questions they identified six themes, four prior to bereavement and two following bereavement. Prior to bereavement these were: loss of familiarity and intimacy (the notion that the illness had taken away the person the carer once knew), loss of hope (acknowledgement that decline was inevitable), grief before death (experiences of grief in response to losses encountered along the illness pathway), and expectancy of death (positive comments associated with prior warning and time to prepare). Themes following bereavement were: post death relief (half of the respondents made reference to release from suffering for their relative and others made reference to their release from the burden of caring) and finally post death reflections (searching for meaning of their care-giving experiences). Those experiencing pre-death grief were likely to report a sense of relief after death but only if good social support was available during and after care-giving.

Along with lay texts, Sweeting & Gilhooley (1997), and Baikie (2002) also identify how informal carers (relatives and friends) sometimes describe their pre- bereavement experience of loss to be so extreme, they feel as if the person they knew prior to the onset of dementia has died leaving only their body or 'shell', and have difficulty treating the individual sufferer as a person with the same value as they had before the illness.

This phenomena is termed 'social death' or 'psychosocial death' where the 'psychological essence, individual personality, or self is perceived as dead, though the person remains biologically alive' (Doka & Aber 2002 cited in Doka, 2004 p.142).

Sweeting and Gilhooley's (1997), study with a mixed sample of carers and level of disability in the sufferers, examined the extent to which social death occurred before the biological death in PWD. They conducted 100 semi-structured interviews with care-giving relatives of PWD and rated the degree to which carers appeared to believe the PWD was socially (or as good as) dead. Carers' perception of social death in their relative was elicited through a series of questions around the following themes: whether the carer believed that the PWD possessed minimal consciousness and contact with the environment, whether they believed the PWD should be treated as a person, if they anticipated the PWD's actual death and if they perceived the PWD's life to have any positive value. Additionally, on the basis of observation and inferences from the comments made, interviewers rated (on a 4 point scale)

both the extent to which the respondent *believed* the person to be socially dead and the extent to which they *behaved* as if the person was socially dead.

They found that over a third of respondents believed and behaved as if the PWD was socially dead, a fifth of respondents believed the PWD was socially dead without behaving as if they were, a third of respondents neither believed nor behaved as if they were socially dead, and finally a very small number of respondents believed they were socially alive but treated them as if they were socially dead.

Unfortunately this study has a number of weaknesses. Although included in the review due the predominance of examples drawn from spouse carers interviews in the analysis of qualitative data, the respondent sample is mixed and no formal attempt has been made to separate out any effects of type of carer relationship i.e. child, spouse and other extended family carers. In addition there is no measure of cognitive or functional disability in the PWD, and the researchers have imposed their frame of understanding in relation to what constitutes the carers' beliefs and behaviours related to the social death of the PWD, rather than explore what the carers actually say about their experiences, and the interpretations they themselves make.

The study by Baike (2002) suggests that whilst spouse carers report at least a degree of social death in their partners there is some evidence for spouse carers of PWD attempting to remain in some way connected to their spouse. Using standardised scales and in-depth interviews to explore the impact of dementia on marital relationships, the study looked at morale of care-givers,

marital intimacy, marital satisfaction and social supports from the spouse and the experience of pleasant events.

Results from the qualitative information (all that is available in published form) indicate that dementia appears to reduce the ability of the sufferer to provide emotional and social support for their spouse. In addition it appears that carers choose to care for their partners, not only because of marriage vows but also because they have experienced a good pre-morbid relationship (*'as if the carers retain an image of their partner as they were before the dementia'* p 293) and have positive experiences within the relationship and what their partner has done for them. Carers referred to personality changes in the sufferer but also times when they glimpsed their partners former self and it was therefore suggests that if the sufferer displays a mannerism or behaves in a way that it a manifestation of their partners previous personality this is emotionally significant for the carer.

In summary therefore, there is good evidence that marital relationship is negatively affected when one spouse develops dementia. Although potentially constrained by the measures employed by studies, and the lack of attention to levels of functional and cognitive impairment in some, the findings suggest that main effects concern the loss of mutuality, companionship and sexual expression. Interestingly however, there is also some evidence that at least for some couples this effect is not accepted passively, but rather attempts are made to retain a sense of 'working together'. In addition there is also support for the existence of anticipatory grief for some spousal carers and indeed social death of the PWD. However, once again the research suggests that

this is not a categorical experience and unaffected spouses continue to remain open to disconfirmatory evidence.

CONCLUSION

The majority of PWD live within the community supported by friends or family. Research indicates that the impact of caring for a relative with dementia brings risks of mental and physical ill health to the carer. The ramifications of this may include negative effects on the quality of life for the carer and sufferer and the standard of care delivered to support the sufferer. In the U.K. a significant up to two thirds of carers will be spouses and because of the increased prevalence of dementia in later life, these spouse carers are more likely to be older people.

Research indicates that female carers have higher rates of psychological morbidity than males and those who have a pre-morbid history of a psychiatric illness are more likely to be negatively affected. There have been conflicting results in the literature relating to sufferer variables which may be important predictors in the level of carer distress or burden experienced, the only consistent finding emerging is that behavioural disturbances in the sufferer tend to lead to more negative experiences for the carer, however there is also some suggestion that there may be within carer variables which influence their response to these difficulties.

A relatively neglected factor in the research literature which may be expected to have an impact on the experience of the carer is the nature of the marital relationship. Research suggests that the relationship may affect, and in turn be affected by, the experience of caring for a spouse with dementia. Carers who during caring perceive their pre-morbid marital relationship as less close have a higher risk of depression and are less likely to report satisfaction and rewards with caring. However there is a need for longitudinal research and studies which are able to control for the potential response bias associated with depression in order to gain greater clarity.

With respect to concurrent marital relationships the main body of research is indicative of closer relationships being associated with better mental health in the carer. However research using a non help seeking community sample suggests that these findings may not be robust across different carer populations. Research using longitudinal designs, different samples (including community samples) and controls for depressed affect are required in order to reliably establish causal pathways.

In regard to the effect of dementia on marital relationship, there is good evidence that marital relationship is negatively affected when one spouse develops dementia, in particular in terms of the loss of mutuality, companionship and sexual expression. Single case studies however, have demonstrated that some carers (and indeed PWD) make active attempts to maintain some of these aspects of the relationship.

In addition there is also some support for the existence of anticipatory grief in spousal carers and indeed the perceived 'social death' of the PWD, however the available research also suggests that in tandem with reporting that they experience their loved one as 'dead' or as a 'shell' the carer continues to remain open to disconfirmatory evidence.

Clinical Implications

Since 1995 carers have had a legal entitlement to an assessment of their needs by Social Services independent of the person they are caring for, and Local Authorities are required to take the results of this assessment into account when making decisions about services (DoH, 1996). These changes have been recently reinforced and reflected in a series of government initiatives. For example in 1999, Caring about Carers a National Strategy for Carers (DoH, 1999) was published. This confirmed the place of carers as a key element in Health and Social Policy and set target for services to support carers including the provision of information, respite and involvement in service planning. Carers have also been given formal recognition in the modernisation plan for the National Health Service (DoH, 2000) which includes as some of its core principles, the notion that services will be shaped around the needs and preferences of individuals, their families and carers. More recently, according to the National Institute for Health and Clinical Excellence Guideline on Dementia (NICE, 2006), good clinical practice should be characterised by routine, proactive and comprehensive assessment and services to meet the needs of carers as they arise.

Research reviewed in this paper suggests that carers of dementia sufferers are at risk of compromised mental and physical health and it follows that vigilance is required from those professionals involved in the care of people with dementia to respond to early signs of depression and physical health problems. Workers should be aware that for spouse carers there is some evidence that this risk is amplified for wives, those who have had a pre-existing mental health problem and carers of PWD manifesting behavioural problems associated with the dementia. These factors should be taken into account when assessing the needs of the carer.

In addition research also suggests that it is important to explore not only current relationship but also carers' perceptions of relationship history in order to understand the attributions made by the carer during caring as this may have implication for how the carer deals with the challenge of caring, their response to behavioural difficulties, and support needs. It is also important to consider how services can support couples in maintaining (or developing) their relationship, for example, by offering advice on how to interact with sufferers to maximise emotional engagement and opportunities for couple work (therapy or counselling to resolve differences and difficulties) where appropriate.

Furthermore, in order to work effectively with carers it is also asserted that it is important to remain cognisant of the potential implications of anticipatory grief potentially experienced by the carer. This grief response itself may lead to increased risk of physical and mental ill health and moreover emotional detachment may also be associated with physical withdrawal. Negative

consequences of this could include feelings of guilt experienced by the sufferer but also possible censure of the carer by professionals who have been professionally socialised into a new 'culture' of dementia care which focuses attention on the key task of maintaining the sufferers' 'personhood' through the social interactions with those who are cognitively intact (Kitwood & Benson 1995). This could lead to staff perceiving carers as 'unfeeling' survivors who do not exhibit the distress that is expected of them in the terminal stages of their loved ones illness, and has implications for designing a support package for the PWD and their carer and also for supervision and support for staff working with this client group.

Future Research

Additional research is required to delineate the differential effects of relationship type (spouse, sibling etc), relationship history and quality on the mental and physical health status of carers. In addition, to compliment the raft of lay literature and published personal accounts there is a need to further investigate the effects of dementia on the marital (and other) relationships. At the same time the sufferers' experience of their relationships needs exploration.

Studies need to guard against implicit assumptions of a causal pathway, and consider using samples drawn from different racial and ethnic groups and carers who are unknown to secondary care services.

Despite the negative toll caring for a dementia sufferer has on spouse carers' mental and physical health status, many carers do in fact continue to care, even whilst reporting anticipatory grief and indeed the 'social death' of their spouse. Early research in the main suggests that if a carer has a positive relationship with or feels a sense of connectedness to their spouse they may appraise the situation in a more positive way and thereby be buffered from the negative consequences of caring. However, more exploratory and qualitative research is required focussing on the carers' perspectives of the perceived impact of both pre-morbid and current relationship functioning on their experience of providing care to a spouse in different stages of dementia, and in particular, the behaviours and activities which enable them to retain (or which threaten) a positive (close) relationship.

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SECTION TWO

**CARING FOR A HUSBAND OR WIFE WITH DEMENTIA – AN
EXPLORATION OF CARERS' EXPERIENCE OF THEIR RELATIONSHIP**

SECTION TWO: RESEARCH REPORT

CARING FOR A HUSBAND OR WIFE WITH DEMENTIA – AN

EXPLORATION OF CARERS' EXPERIENCE OF THEIR RELATIONSHIP

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**CARING FOR A HUSBAND OR WIFE WITH DEMENTIA – AN
EXPLORATION OF CARERS' EXPERIENCE OF THEIR RELATIONSHIP**

ABSTRACT

Objectives:

This study explored spouse carers' experience of their relationship with their husband or wife in the later stages of dementia.

Design:

Interpretative Phenomenological Analysis was the qualitative method of choice for this study.

Methods:

Ten spouse carers (six wives and four husbands) of people suffering from severe dementia (Mini-Mental Status Examination ≤ 10 Folstein et.al., 1975) were recruited through contact with secondary care services. Participants took part in a semi structured interview which was transcribed and analysed.

Results:

Five interrelated processes (with 19 sub-themes) were identified; Establishing connections and forming a lasting relationship, Experiencing dementia as a threat to the relationship, Attempting to maintain the existence of a relationship, Desire to care and Experiencing the impact of caring on wellbeing.

Conclusions:

The importance of carers' past and present marital relationship whilst providing care to their spouse with advanced dementia is supported. Insights into both how carers sustain a relationship with their spouse whilst reporting a sense of loss of the relationship or the person they once knew, and the impact of caring on their wellbeing are offered. Implications for clinical practice and ideas for future research are summarised.

**CARING FOR A HUSBAND OR WIFE WITH DEMENTIA – AN
EXPLORATION OF CARERS' EXPERIENCE OF THEIR RELATIONSHIP**

INTRODUCTION

It is estimated that by the year 2025 there will be one million people suffering from dementia in the United Kingdom (Alzheimer's Society, 2007). Assuming there will be no revolutionary advances in the treatment or management of dementia, or societal restructuring, it is anticipated that the majority of people with dementia will continue to live in the community supported by family and friends. The demographic profile of carers remains unclear although it is estimated that in the U.K. up to two thirds are spouses of the person with dementia (Brodaty & Green, 2000).

Research indicates that carers have a higher risk of mental health difficulties, in particular, elevated morbidity in terms of depression, (Gafstrom et.al., 1992, Baumgarten et.al. 1992, Schulz, et. al. 1995 and Cuijpers, 2005) and those with a previous history of psychiatric illness are more likely to experience a (re)occurrence after the onset of caring than those without (Russo et. al., 2003). In addition a meta-analytic study suggested that carers have slightly increased risk factors for physical illness including higher stress hormones and lower levels of antibody responses than non carers, (Vitaliano et.al., 2003).

Factors including demographic variables, carer and sufferer characteristics have been investigated as potentially related to the genesis of depression, stress and burden in carers of people/persons with dementia (PWD).

However, there is still a lack of clarity about the relative influence of these variables. This may be explained by the fact that many studies are often without control groups and based on small, heterogenous samples (e.g. combine spouse, sibling and child carers) who are recruited through formal support networks (thereby possibly comprising a relatively 'unhealthy' sample), and use variety of measures some of which have been specifically developed by the researchers and used in studies before their psychometric properties have been properly examined (Wijeratne, 1997).

One consistent finding however is that female carers are more likely to suffer from depression than males (Cuijpers, 2005) and there is some indication that behavioural disturbances manifested by the PWD are associated with a negative impact on the carers well-being (Brodaty & Hadzi-Palovic, 1990 and Cohen, et.al., 1997) and that passive rather than excessive behaviours have the greatest negative impact on the relationship (de Vught et.al., 2003).

However, de Vught (2005) suggests that it is the carers' response to behavioural difficulties manifested in the sufferer rather than the behavioural difficulties themselves which determines nursing home placement, and Pruchno & Resch, (1989) suggest that those who tend to utilise effective coping strategies (e.g. problem-solving) report greater well being and lower scores on measures of perceived burden. In addition racial and cultural beliefs about dementia may affect how families both respond to the challenges of caring and the interventions designed to support carers (Haley et.al., 1998 and Connell & Gibson, 1997).



Despite the evidenced negative impact on many carers' mental and physical health, carers often continue in their caring role. An often overlooked factor in the research, which may help account for this desire to continue caring, is the relationship between sufferer and carer i.e. how much the person and the relationship with the person is affectively valued by the caregiver, e.g. feelings of emotional closeness, having positive sentiment towards them and having shared values and beliefs, (Lawrence et.al., 1998). This oversight is surprising, given the growing acknowledgement that the PWD's presentation is partly shaped by their personal experience (the individual continuing to search for meaning in the context of lifetime experiences) and relational contexts (in which social interactions help maintain social identity, value and worth), Cheston & Bender (1999).

Whilst developing a model to explain the effects of caring, Pearlin et. al. (1990), proposed that the background and context of caring (including pre-morbid relationship) leads to primary stressors, secondary role strains and secondary intra-psychic strains. Within this model, relationship quality is viewed not only as a product of the stressors, but also as providing a 'particular lens through which stressors are interpreted or appraised', (Lawrence et. al, 1998). Thus, relationships can either play a mediating or moderating role within the carers' experience of care-giving.

In the mediating role as stressors increase the quality the relationship suffers. Relational deprivation or negative reappraisal of the marital relationship can develop from carers feeling deprived of a relationship with a significant other and loss of an affectionate exchange as the dementia progresses, which in turn affects the quality of life of carers and continuity and quality of care for the

sufferers. Within the moderator role the relationship has the potential to modify the impact of the stressors i.e. if the carer feels emotionally close to a sufferer they may appraise the situation more positively and thereby be buffered from the negative consequences of caring. Thus a carer with a strong positive relationship may feel less burdened and stressed relative to somebody with a poor relationship despite similar care giving situations and comparable objective stressors. However, it is likely that both processes occur simultaneously i.e. the quality of the relationship will affect the carer's perception of stressors and thus potentially buffer the carer from negative consequences, and the quality of the relationship may be altered by the presence of stressors which will increase negative consequences for the carer (Pruchno & Resch ,1989).

Research exploring the effects of marital relationship has provided information in three categories; the effects of pre-morbid relationship, the effects of the concurrent marital relationship and the effects of dementia on the marital relationship. Research suggests that those spouses who during caring report a poor pre-morbid marital relationship also report higher rates of depression (e.g. Morris et. al. 1988, Krammer, 1993, Ballard,et. al., 1995, Williamson & Shaffer, 2001). However, methodological weaknesses, in particular, the lack of attention to the potential response bias as a consequence of the carers' depression prevent clarification of a causal pathway. Longitudinal studies are therefore required and qualitative research exploring the subjective meaning of pre-morbid relationships from both the carer and care recipient perspectives, before and during caring would be helpful in illuminating the carer and PWD experience.

Research also suggests that current marital functioning is associated with carers' emotional wellbeing, and that on the whole more positive relationships are indicative of better mental health (e.g. Lewis et. al., 2005, Rankin et. al., 2001). However, it is possible that there are gender effects with wives being more susceptible to depression and a differential impact in terms of the various aspects of the relationship available e.g. emotional versus instrumental support. Unfortunately causal pathways remain unclear and further longitudinal studies and studies controlling for the potential bias of depressed affect are required. In addition qualitative research exploring the carers' and PWD's experience of their relationship during dementia and its influence on the carers' and sufferers' wellbeing is required.

The largest body of research concerning marital relationships and carers is the impact the dementia itself has on the marital relationship. Most of this research has concentrated on the perspective of the carers with notable exceptions in the form of single case studies which have also included data from the PWD themselves. Overall, there is good evidence that marital relationship is negatively affected when one spouse develops dementia e.g. Eloneimi-Sulkava et. al., (2002), Wright (1991), Wright (1998) and Beeson (2003). Although potentially constrained by the measures employed by studies, and the lack of attention to levels of functional and cognitive impairment in some, the findings suggest that main effects concern the loss of mutuality, companionship and sexual expression. Interestingly, there is also some evidence from single case studies that at least for some couples these effects are not accepted passively, but rather attempts are made to retain a

sense of 'working together', e.g. Hellstrom et.al.,(2005) and Daniels et. al., (2007).

Some researchers have also suggested that depression in carers may be more usefully conceptualised as a manifestation of anticipatory grief (Walker & Pomeroy, 1996 and Collins et. al., (1993), i.e. the grief responses (mourning and detachment) in people who were not yet bereaved but who had been separated from their loved one Lindemann (1944).

Furthermore, Sweeting & Gilhooly (1997), Baikie (2002), and Adams & Sanders (2004) also identify how informal carers (relatives and friends) sometimes describe their pre- bereavement experience of loss to be so extreme, especially in the advanced stages of dementia, that it may represent the social death of the PWD where the 'psychological essence, individual personality, or self is perceived as dead, though the person remains biologically alive' (Doka & Aber, 2002 cited in Doka, 2004 p.142). Traditional models of bereavement assert the task of mourning is to withdraw emotional energy from the loved one in order to reinvest it elsewhere (Worden, 2003), whereas more recent models influenced by cross cultural literature and case accounts, propose ongoing attachment to the deceased is integral to successful adaptation to bereavement. Thus, the purpose of grief is no longer seen as severing the bonds between living and dead, but to use ongoing attachment ('continuing bonds') to foster continuity of identity, reinforce coping efforts and provide comfort and support during transition to a new life (Bonnano & Kaltman,1999).

This concept of 'continuing bonds' may have applicability in understanding the experience of caring for somebody with dementia and explain why in tandem with reporting that they experience their loved one as 'dead' or as a 'shell' the carer continues to remain open to disconfirmatory evidence (Baikie, 2002). Once again however there remains a paucity of qualitative research exploring from the carers' perspective, the impact dementia has on their marital relationship and their experience of maintaining (or indeed perhaps losing or changing) this relationship in the presence of dementia in particular in the advanced stages of cognitive decline.

Aims of Present Research

This study aims to extend present knowledge by focusing on spouse carers' experience of their relationship with their husband or wife as they are in the later stages of dementia. It will aim to:

- Explore carers experience of their relationship with their spouse prior to the onset of dementia and how this is maintained or altered;
- Explore carers experience of their relationship with their spouse during the later stages of the illness;
- Explore whether and how carers feel their experiences of their relationship influences their ability to care; and
- Explore whether and how carers feel their experiences of their relationship influences their wellbeing.

METHOD

Chosen Methodology

This study comprises an exploration of the carers' experience of their relationship with the dementia sufferer in the later stages of dementia from a phenomenological point of view and by interpreting and reflecting on the perceptions and experiences of the carers. It proceeds from the assumption that there is a common identifiable 'structure and essence' (Patton, 1990) in the experiences of carers which is both theoretically interesting and clinically useful.

Where 'patterns of meaning, interpretation and understanding inherent within the individual's experience' are the subject of interest, qualitative methods are considered most appropriate (Turpin et. al., 1997 p4), and this is particularly the case where it is not clear what questions would be relevant to ask through quantitative research, (Marshall & Rossman, 1995). In addition to being grounded in a philosophical position which is 'interpretivist' (i.e. '...concerned with how the social world is interpreted, understood, experienced or produced...' Mason 1996, p4) qualitative research is also 'based on methods of data generation which are flexible and sensitive to the social context in which data is produced' and 'based on methods of analysis and explanation building which involve complexity, detail and context'. (Mason, 1996, p4).

Within the present study it was seen as important to explore the participants view of the world, to adopt as far as possible the 'insider's perspective' of the

phenomena under study, whilst recognising and acknowledging that the researchers interpretation of meaning influences the analysis (Smith, 2003). The issues under study are complex, related to process and are both very personal and potentially controversial. Such issues lend themselves to exploration through semi-structured interviews and interpretation by means of qualitative analysis Smith et. al., (1995). Thus, qualitative methodologies were considered to be epistemologically appropriate.

A number of qualitative methodologies are in existence e.g. discourse, conversation and narrative analysis, grounded theory and Interpretative Phenomenological Analysis (IPA), and careful consideration was given to the choice of qualitative method which would be most suitable for the aims of this particular research. Discourse, conversation and narrative analysis are more concerned with studying the linguistic resources participants draw on during conversations, the patterns conversations take, and the social interaction work being performed during them whereas the emphasis of the study is exploring the 'life-world' of the participants or understanding how the participants make sense of their social world. (Smith et. al., 1999). Grounded theory, although similar in many ways to IPA, aims to explore social processes and to inductively develop theory. Using this methodology 'concepts and relationships among them are not only generated but they are also provisionally tested' (Strauss & Corbin, 1990 p24). IPA in contrast focuses on analysing and describing individual subjective experiences and perspectives which are more the focus of this particular study. Therefore, IPA was identified as being the method of choice for this enquiry.

Sampling Strategy:

Arising from the chosen methodology for this research with its emphasis on idiographic rather than nomothetic approach a relatively small sample size was considered appropriate. Whilst published IPA studies report sample sizes of between 1 and 15 participants, Turpin et. al. (1997), suggest trainee clinical psychologists secure between 8 – 20 participants for studies using qualitative methodologies.

For the purpose of this particular study in view of the richness of material it was anticipated would be yielded from the interviews, a maximum of 12 participants (including up to 2 providing pilot interviews) were sought. Participants were recruited through contact with Community Mental Health Teams (CMHTs) within Derbyshire Mental Health NHS Trust.

A purposive sampling strategy was invoked to identify a closely defined homogenous sub-group of carers for whom the research question was relevant to allow exploration of experiences.

Inclusion and Exclusion Criteria

Carers were invited to take part in the study if they were still caring for their spouse at home and were aware of their husband/wife's diagnosis of dementia. (Spouse carers of individuals suffering from any type of dementia were included). Earlier research has identified that the greatest impact of dementia on relationships is in the severe stage of dementia (Adams &

Sanders, 2004) therefore only those caring for somebody in the latter stages of dementia as routinely assessed by the CMHT on Folstein et. al.'s (1975), Mini-Mental Status Examination (score ≤ 10) were included. To facilitate understanding between the researcher and carer only those carers fluent in English were included. Carers were excluded if they known by the CMHT to be suffering from a serious mental illness which may have been exacerbated by taking part in the study.

Participants:

The sample comprised 10 carers, 4 men and 6 women. *Age of participants:* Participants ranged in age between 66 and 84 years with an average age of 75.5 years (76 years for husband carers - range 66-81years, and 75 years for wife carers - range 66-84 years). *Age of those cared for:* The individuals suffering from dementia (4 women and 6 men) ranged in age between 68 and 87 years with an average age of 76 years (71 years for wife sufferers- range 63 -77 years, and 79 years for husband sufferers - range 68 -87 years). *Nationality:* All participants were white British married to white British with English as their first language. *Marriage:* All participants reported that the relationship being discussed was their and their spouse's first marriage. The length of marriages ranged from 42 – 65 years with an average of 50 years. For husband carers this was 47.5 years (range 42 -56 years), for wife carers this was 52 years (range 42 – 65 years). *Dementia:* All participants recognised that their partner was suffering from severe dementia with husband carers reporting that their wives were diagnosed as suffering from Alzheimer's disease (2), mixed dementia (1) and Lewy Body Dementia (1) and wife carers

reporting that their husbands had received diagnoses of Alzheimer's Disease (4) and Vascular Dementia (2). The average duration of dementia was estimated as 6 years ranging from 3 to 14 years (4 years for husband carers - range 3 -5 years, 7 years for wife carers - range 3-14 years). Average length of time since formal diagnosis was 3.5 years (range 6 weeks – 9 years). For husband carers the time since their wife's formal diagnosis was calculated as 2.5 years - range 18 months - 4 years and for wife carers the time since their husband's diagnosis was an average of 4 years - range 6 weeks to 9 years.

Socioeconomic group: The geographical areas covered by the recruiting CMHTs were generally urban and it was noted that the sample of carers recruited included individuals from both middle and lower socioeconomic class groupings. *Representiveness of the sample:* Data on the factors outlined above are recorded on individual case files and are not routinely aggregated by the service. However through discussion with individual team members and through team meetings it was established that the participant sample was typical of the carers who presented to the secondary care services in terms of type and duration of illness and also length of time since diagnosis and referral into services and therefore was not skewed.

One husband carer and one wife carer declined to take part. The wife carer reported that she found it too difficult to discuss her situation with strangers and the husband carer was still working and was unable to give the time necessary to take part. In addition, one interview was cancelled by mutual agreement as the circumstances for the carer had changed with her husband being admitted into full time residential care as a result of a crisis situation, and

another interview was sensitively abandoned by the researcher as a result of interruption by the PWD.

Procedure:

Approval for the research:

Prior to approval being sought from the local research ethics and governance committees and in addition to independent external review, comments on the research proposal were invited from the Co-ordinator and members of the Derby branch of the Alzheimer's Society. These were taken into account during the final drafting of the proposal before formal approval for the research was sought and granted by Derbyshire Research Ethics Committee, Derbyshire Mental Health Trust Research Committee and Sheffield University (Research Governance Sponsor). (Copies of letters of approval can be found in Appendix 2.)

Ethical issues:

A number of ethical issues were considered and addressed, these included:

a) the requirement for interviews to take place in private (participants were advised that to ensure confidentiality and to enable them to talk freely and without interruption it was necessary for the interview to take place without the presence of their husband/wife);

b) participant confidentiality (in addition to the researcher assuring that they would protect confidentiality, checks were made to ensure the transcriber did not know the participant and signed a confidentiality declaration);

c) conditions under which there may be breach of confidentiality (i.e. if there was disclosure of risk to either participant or the PWD);

d) involvement of the PWD in decision making relevant to the study (As carers were routinely offered assessments and care plans as service users in their own right, and the research focused on *their* perspective or *their* relationship it was considered appropriate for the members of the CMHT to approach them directly without requesting the permission of the PWD. Also because it was likely that the PWD would lack capacity to consent to additional services to enable their carer to be interviewed alone, a decision was made to arrange for additional carer respite services for the duration of the interview only if this could be arranged through existing service provision and if there was evidence that the PWD's wellbeing would not be compromised);

e) security of the transcripts (tapes and transcripts were to kept in a locked filing cabinet in a locked office when not in use and in electronic form transcripts were anonymised and held on a password protected system); and finally;

f) safety of the researcher (the researcher was required to adhere to the host Trust's Working Alone in Safety policy).

Participant Recruitment Process

CMHTs were visited by the researcher and the aims of the study, criteria for participant inclusion / exclusion, issues related to confidentiality and participant recruitment were discussed. Team members were given a sheet summarising this information (see Appendix 3) and asked to provide information leaflets to those carers who were eligible to take part (see Appendix 4). Interested carers were asked to provide contact details on a form which was returned to the researcher. The researcher then made telephone contact with the carer, answered any questions and if the carer agreed to take part in the study, arrangements were made to meet to conduct the research interview. The researcher asked the carer/participant to read and sign consent forms on meeting after introductions before commencing the interview (see Appendix 5).

Although participants were offered a choice of interview location, all opted to be interviewed in their own homes and where care was required for their spouse, interviews were arranged during normal respite arrangements at the request of the participants.

Data Collection

One of the central principles of qualitative research is that data collection technique should minimise data reduction, 'allow participant generated meanings to be heard' and to be flexible to enable 'the emergence of new, and unanticipated, categories of meaning and experience (Willig, 2001,p15). Thus

individual audio-taped semi-structured interviews lasting between 40 and 90 minutes were used to collect the qualitative data.

After briefly reminding the individual of the reasons for the study and obtaining their written consent to take part participants were asked a few structured questions in order to contextualise the data (See Participants section above). Following this was a short introduction to the semi-structured interview which invited participants to offer their own experiences in their own words. A Topic Guide (see Appendix 6) and prompts were used, however the researcher remained flexible about the ordering of questions to ensure the interview flowed as smoothly as possible and to allow exploration of additional issues/themes introduced by the participant (Smith, 2003).

At the end of the interview, the researcher checked the participant was not experiencing any lasting distress as a result of taking part in the interview. Although several carers had become quite tearful on occasion during the interview, at the end all reported that they were not distressed and four participants spontaneously commented that they had found the interview useful in terms of offering them an opportunity to reflect on their relationship with their spouse.

Pilot interview:

The first interview was considered a pilot. This interview was audio recorded, and transcribed by the researcher prior to conducting further interviews for the main research study. In addition, feedback was provided by the researcher's

supervisors. This enabled the researcher to become more familiar with the topic guide in use, to check on the neutrality and effectiveness of the questions and probes etc and to gain confidence at timing the interview to ensure all topics were covered. As only slight amendments to the topic guide and interview style were made data from the pilot interview was be used in the main research analysis (Smith, 2003).

Method of Analysis:

Interviews were analysed using the method outlined by Smith, (2003). The researcher initially concentrated on one transcript and listened to the tape whilst reading the transcript several times in order to become as familiar as possible with the account. During reading the researcher made attempts to summarise or paraphrase, and to note associations, connections or preliminary interpretations which came to mind, commenting upon similarities, differences, amplifications and contradictions in what the participant said. The transcript was then reread and emerging title (or higher level) themes were identified and documented ensuring that these themes were still clearly identifiable as being rooted in what the participant said and the initial impressions of the researcher. The emerging themes were then listed on a piece of paper and connections between the themes and super-ordinate concepts identified. (At the same time the original material was referred to in order to check understanding and interpretation against what the participant actually said). At the end of this process a list of super-ordinate themes was generated identifying clusters which most strongly captured the participant's concerns about the topic.

References to the sources within the transcript were made to aid future searches.

This process was repeated for each of the remaining transcripts, and whilst analyses of previously read transcripts informed subsequent analyses, the researcher remained open to the possibility of identifying new and contradictory themes in each transcript. After each transcript was analysed by the interpretive process, a 'Who Said What' table was drafted to identify super-ordinate themes (see Appendix 7). However at all points the original transcripts were referred to in order to ensure that there was a sound basis rooted in the raw transcripts for each of the themes identified.

Quality Control:

After the pilot interview, all subsequent interviews were transcribed by a professional secretary who had experience of transcribing qualitative interviews. To reduce transcription error, guidance on notation was given in respect to identifying information e.g. the use of pseudonyms, conversation fillers, inaudible sections, emotional content and unfamiliar terminology, and opportunity for debrief was offered (MacLean et.al., 2004) In addition, in order for the researcher to become as familiar as possible with the transcripts and to check for accuracy and interpretation of meaning, each tape was listened to whilst reading the transcript.

Strategies to ensure validity included the researcher writing a reflexive journal throughout the research process to assist in the maintenance of the

researcher's awareness of participant observer status, (Henwood & Pidgeon, 1992) allowing the effect of such thoughts on emergent themes to be auditable. Also a two stage audit of the detailed coding was carried out by the two research supervisors (two Clinical Psychologists with extensive experience of qualitative methodology and analysis) to provide a process through which validity and credibility could be established. The first stage entailed the supervisors reading two transcripts and independently coding and identifying emergent themes which were then discussed in detail in a three-way meeting with the researcher. During this meeting similarities and differences in the interpretation of the themes were discussed which supported further reflection and validity checking by the researcher during subsequent analyses. In the second phase the researcher provided details of coding and emergent themes with relevant quotations referenced to the context and text within all ten of the transcripts together with a list of derived super-ordinate processes or themes. A further three-way meeting checked that there was transparency in the coding and identification of themes ensuring that these were rooted in the actual transcripts and allowed for the verification of the development of the super-ordinate themes. An example of data in the form of an annotated passage of transcript to illustrate both the analytic procedure and understanding developed from it can be found in Appendix 8.

In addition the researcher adhered to a number of other guidelines for conducting methodologically rigorous qualitative research as recommended by Elliot et. al., 1999. More specifically, the researcher shared their perspective with readers (see below), situated the sample by `describing the participants and their life circumstances to aid the reader in judging the range of persons

and situations to which the findings might be relevant' (Elliot et. al., 1999, p221), and finally, has attempted to resonate with readers by presenting it in a way that is intended to clarify or expand their appreciation or understanding of the topic.

Researcher's Perspective:

The researcher is a white British woman aged in her mid forties with experience of working as a Clinical Psychologist within Older Peoples' Mental Health Services. The researcher is therefore accustomed to engaging older people with a range of mental health difficulties and their carers in sensitive and emotive interviews. The researcher had become interested in spouse carers' experiences of their relationship with their husband or wife through clinical practice and was aware of several cases where the carer described how they felt as if the PWD they were caring for had 'died' whilst at the same time were trying to maintain a form of relationship with the PWD. However, rather than adopt this premise for the research, a more open perspective was adopted to allow the carer's experience of relationship to emerge.

FINDINGS

The analysis produced five interrelated processes: Establishing connections and forming a lasting relationship, Experiencing dementia as a threat to the relationship, Attempting to maintain the existence of a relationship, Desire to care and Experiencing the impact of caring on wellbeing. These processes were derived from 19 sub-themes (see table 1 below).

Table 1: Processes and Associated Sub-themes

Super-ordinate Processes	Sub-Ordinate Themes
1. Establishing connections and forming a lasting relationship	1(a) `Just knowing` 1(b) Compatibility 1(b)i Shared Interests 1(b)ii Personality 1(b)iii Similar Social Background 1(c) Partnership 1(d) Individual vs Couple Identity
2. Experiencing Dementia as a threat to the relationship	2 (a) End of the relationship as it was 2 (b) Death of a spouse
3. Attempting to maintain the existence of a relationship	3 (a) Seeking a response 3 (b) Remembering the person/relationship 3 (c) Sustaining routines and interactions 3 (d) Recognising the impact of dementia
4. Desire to care	4 (a) Responsibility 4 (b) Reciprocity 4 (c) Honouring the past
5. Experiencing the impact of caring on wellbeing	5 (a) Fear 5 (b) Entrapment 5 (c) Guilt 5 (d) Sadness and loss 5 (e) Sense of Achievement 5 (f) Reciprocated Affection

1. Establishing connections and forming a lasting relationship

Without exception participants were able to recall, often in some detail, the circumstances around meeting their spouse and the development of a relationship. For some the attraction was immediate whereas for others this developed through getting to know one another and establishing compatibility.

1(a) `Just knowing`

Four out of the ten participants described how at first meeting, they felt a sense of attraction or connection.

Participant 2: *"there was this, I dunno we seemed to hit it off straight away... we seemed to be a natural [couple]"*

Participant 5: *" It was as if I knew that he was the person for me from that first night"*

Participant 7: *" we just clicked"*

Only one participant described some ambivalence in the beginning, but went on to describe the development of a close relationship.

Participant 3: *"we had a love- hate relationship at first"*

1(b) Compatibility

Three themes (described overleaf) emerged as being important to participants for assessing compatibility; shared interests, similar or compatible personality and similar social backgrounds.

1(b)i Shared Interests

Eight out of ten participants identified either having established similar interests or the capacity to develop shared interests as an important factor for the development and maintenance of relationship.

Participant 2: “ *we found we had a lot of different things in common, different things which we would like to do..... it wasn't I'm interested because he is, or I'm interested because she is, as we were both interested*”

Participant 3: “ *we enjoyed walking with our dogs our dogs we're..., we're both animal lovers*”

Participant 4: “ *we liked the same sort of things you know more or less...*”

1(b)ii Personality

For some participants (seven out of ten) sharing a personality characteristic with their spouse or perceiving themselves as having complimentary personalities was important, and particular value was given to having a shared sense of humour.

Participant 7: “ *I mean he was quiet and I was never an extrovert type of person*”

Participant 9: “*we were on a similar intellectual level*”

Participant 4: “*we used to laugh a lot*”

1(b)iii Similar Social background

For six participants there seemed to be an implicit recognition that social background had been significant in the choice of partner, and in particular the ability to be accepted into each other's family.

Participant 2: "*mine and [name of wife] 's family came from the same [name of county]*"

Participant 10: "*we had good relationships with his family and with my family*"

Participant 8: "*I thought they was a nice family*"

1(c) Partnership

Six out of the ten participants clearly thought of the relationship as a partnership characterised by an exchange of practical and emotional support and help, e.g.

Participant 2: "*we encouraged each other in what we were in*"

Participant 3: "*he always looked after me as I looked after him*"

Participant 9: "*we're a partnership, we've always had a partnership*"

An additional two female participants described partnerships with their husbands which seemed more traditional and practical in nature with roles being divided according to sex role stereotypes e.g.

Participant 10: "*he went out to work, you were there to get his food and keep house*",

Participant 5: "*[name of husband] was and still is one of the old school that housework etc is a woman's job and the exterior etc is a man's job*"

However, both made reference to the fact that although they had accepted this, the adherence to role was a source of frustration to them e.g.

Participant 5 “ *I did very often feel that under the circumstances he could have helped more...and had he given a little it would have saved having to have those arguments*”

1(d) Individual vs Couple Identity

For four participants the sense of partnership with their spouse seemed complete, and their individual identity was outweighed by their sense of couple identity.

Participant 2: “*we’ve always been the two of us, rather than me having friends and [name of wife] having friends.....we were self contained as a couple and we didn’t need anybody else*”

Participant 4: “*you’ve been together so long it is as if you’ve lost your right arm if he wasn’t here*”

Others described valuing throughout their marriage, a sense of individual identity.

Participant 7: “*I wouldn’t want a relationship where I didn’t feel I could do things with my friends*”

Participant 9: “*we weren’t in each others pockets we did different things*”

2. Experiencing Dementia as a Threat to the Relationship

Nine participants expressed a degree of confusion in respect of their marital relationship as a consequence of their spouse suffering from dementia reporting that they felt that the relationship with their spouse prior to the dementia had ended, or even, that the person they had once known as their spouse had died. At the same time however, participants were engaging in activities which appeared to be trying to maintain the bonds between them. (The participant who did not explicitly voice either of these beliefs was caring for her husband who was still actively trying to verbalise his needs and was displaying challenging behaviours, including physical aggression towards her).

2(a) End of the relationship as it was

Six participants also made specific reference to the fact that the relationship which they had once shared with their partner had become one-sided e.g.

Participant 2: *"I'm doing all the caring whereas before we shared our life...I've taken over two roles now"*

Participant 5: *"A relationship to me is two people sharing; we are now sort of two separate people because of the dementia, so to me it isn't a relationship anymore"*

Participant 9: *"...it's not a relationship as it was, it isn't two-way anymore"*

2(b) Death of a spouse

Six out of the ten participants made reference to the fact that at some level they believed that the `essence' of person they had known as their husband or wife had `died' leaving behind only a physical presence or `shell' e.g.

Participant 2 “ it's like [name of wife] has gone and I'm left caring for her body.....it's just like she's died yet in some ways she is still here.....it's like a little girl playing with a doll and you can get a doll to do anything”

Participant 3: “I can see that he is like an old man and a shell of a man.....makes me realise that he's really gone as the old [name of husband]”

Participant 6: “that's not the [name of husband] that I married, he's there but he's not there..... it's like a death but he's still here”

3. Attempting to maintain the existence of a relationship

In juxtaposition to the participants' experience of the end of their marital relationship as they understood it, or the `death' of the person they once knew as their spouse, were their attempts to engage in activities which appeared to be trying to maintain bonds between them.

3 (a) Seeking a response

All participants placed value on being able to identify responses from their spouse (especially signs of pleasure), albeit for some very fleeting, which they understood as representing a continuity of their person and presence, e.g.

Participant 3: *“he wouldn’t put up with me telling him what he must do, never would, and even now he’s very stubborn”*

Participant 2: *“ there is nothing nicer than when you do something and she smiles – she knows she is being cared for”*

Participant 5: *“occasionally I get a response and it makes me think that somewhere in the back of his brain there is something functioning, a little spark”*

Participant 6: *“ He enjoys his meals his mouth is ready and open and I tell him he’s like a bird sometimes but in his way he can sort of tell me he wants to drink or he’s hungry because his mouth will come open, and then I suppose you think, you know ‘you’re there to do that’ “*

3 (b) Remembering the person/relationship

Eight out of the ten participants spoke about the positive attributes their spouse had, or the positive aspects of the relationship they had experienced with their spouse over the years. Of note however was the frequent use of the past tense to describe these, e.g.

Participant 1: *“ we had a lot of happy times together a lot of pleasure together”*

Participant 2: *“: “anybody new who comes in I make sure they know about her achievements, I’m still proud of what she achieved”*

Participant 7: *“I know he was a very gentle person”*

Participant 8: *“she was so happy not a bad word for anyone”*

And only one participant mentioned anything negative from the past about their spouse or any unresolved relationship issue:

Participant 5: *"[name of husband] is not a person who has ever been a person to go out and buy presents or to write cards or anything like that.....I was always a little bit sad that his attitude was like that , I felt that perhaps it was part of his upbringing"*

3 (c) Sustaining routines and interactions

Seven participants talked about the importance of maintaining old routines and interactions in keeping a sense of connection with their spouse, even though on occasion there was recognition that this might not be the most appropriate for their husband or wife e.g. one participant talked of how she had booked a number of holidays as this was something that had been a part of their lives together whilst at the same time recognised that her husband had deteriorated and may not cope with travelling.

Participant 1: *"we have our bits of fun, when she is alright I dance around the room with her"*

Participant 2: *" I talk to her as though, she you know understands, and I know it doesn't make any sense to her but I talk to her to discuss things with her...I get the right answers now of course"*

Participant 6: *"I talk to [name of husband] and say `you should be doing this you know' I know he can't understand me or hear me but it makes me feel better"*

3(d) Recognising the impact of dementia

Several participants (six) described how at times they has misinterpreted the behaviour of their spouse as representing deliberate or thoughtless acts and

their initial response of irritation and emotional withdrawal. The reframing of these experiences as arising from the illness and outside the control of their spouse appeared important in the re-establishment of relationship.

Participant 7: *“ he hasn’t a clue he’s being horrible...initially you don’t handle things right because you don’t recognise that it’s part of their illness but then you gradually realise it switches on and off and he can’t help it”*

Participant 2: *“ I remember the first time she was incontinent I was so angry....and I remember distinctly, quite distinctly the regret that I had after being angry with her and er realising that she couldn’t, couldn’t help it..”*

Participant 9: *“she can’t help what she is doing although initially the acceptance isn’t there”*

However one carer (who had initially described their relationship as love –hate) continued to believe that her husband was acting in an uncaring manner or deliberately to annoy her and said that this resulted in her disliking and resenting him.

Participant 3: *“I think you cruel devil”* (when her husband failed to acknowledge the pain she experiences from her physical difficulties) and *“Some of the time I can’t believe that he doesn’t know what he is doing... Although I know he’s got dementia there is still some part of me that doesn’t believe that’s true..... if he can be crafty like that then he must know that its wrong* (referring to times when her husband does not help around the home and spits in the sink when she is not in the kitchen).

Another carer described how he was struggling to accept his wife's illness.

Participant 8: *"I wonder, why has all this happened like this? You know....I just can't accept it"*

4. Desire to care

All participants talked about their motivation to continue caring for their spouse despite reporting that their lives were dominated by caring activities, and experiencing negative impacts on their own quality of life. In particular participants reported sleep deprivation, tiredness, exacerbation of their own physical problems, a need to be 'thinking for two' and to be vigilant at all times in order to anticipate and avoid difficulties in caring for their spouse. Three carers talked about their spouse exhibiting physical aggression as a result of the changes associated with dementia¹.

4 (a) Responsibility

Nine out of the ten participants referred to feeling a sense of responsibility for the care of their spouse, and some believed that only they were able to provide the quality of care they would wish for their spouse.

Participant 1: *"she needs care, she needs looking after and I'm the one to do it"*

Participant 4: *"I feel this very strong sense of responsibility"*

Participant 1: *"I don't like her to suffer more than she has to"*

¹ Services were aware of these potential risks in each case

Participant 7: *“ there is all sorts of little things I do and I think ‘they won’t do this and they won’t do that’ and I know they are things that help him”*

However, one carer wondered if they were prolonging their own and their partner’s suffering by providing high quality care at home but felt that it was inconceivable not to care.

Participant 6: *“ sometimes you think well, erm if you hadn’t looked after him all these years where would you be now... erm people say that he wouldn’t be here, and so are you prolonging the agony? But you couldn’t hurt him, you’ve just got to look after him... you can’t do it any other way”*

Only three out of the nine referred to this sense of responsibility as a formal ‘duty’ they had accepted as part of their marriage contract or vows.

Participant 3: *“ my age group, that was how you were brought up and erm you sort of, it was your responsibility, that was it sort of thing”*

Participant 10 *“.. it’s my duty”*

4(b) Reciprocity

Seven participants reported that they believed, had the situations been reversed and they had developed dementia, their spouse would have looked after them.

Participant 1: *“we’ve been together all these years, she would have done the same for me”*

Participant 2: *“If the boot had of been on the other’s foot then she would have done exactly the same”*

Two of these participants believed that their spouses had previously looked after them during periods of their life together and caring for them was an opportunity to repay the care they had received.

Participant 1: *“ she was always there to help me and that has reflected in the way I want to help look after her”*

Participant 8: *“ she used to look after me cook me meals and everything and I think well it’s come to me now and I’ve got to look after her now”*

4 (c) Honouring the past

Most participants (eight) reflected on their shared history with their spouse and a sense of investment in each other and the relationship which prevented them from relinquishing caring. For many, the thought of seeking full time care for their spouse outside their marital home seemed to be perceived as contemplating abandoning the other.

Participant 2: *“ you can’t throw away 50 years because somebody is ill”*

Participant 5: *“we’ve been a partnership for 50 years, you don’t just suddenly sever a partnership because of Alzheimer’s, you don’t desert them because they’ve got dementia.”*

5. Experiencing the impact of caring

When participants shared their experiences of the impact of caring on their wellbeing, several participants became tearful and upset and emergent themes were almost all negative. Four interconnected themes were identified accounting for negative experiences; fear, entrapment, guilt, sadness/loss and

two accounted for positive experiences caring; sense of achievement and reciprocated affection.

5(a) Fear

Two participants, both female, described how they felt afraid of their husband's behaviour.

Participant 4: when describing how her husband had tried to get out the house by sawing through the door handle *"..it's the worry you know er sort er a bit frightening you know, I'm frightened of him doing something drastic and that and he won't listen to you"*

Participant 7: who had recently had fingers broken during attempts to assist him in toileting *"...I know how aggressive he can get and I'm wary and stand off"*

A further three participants talked of their fear that they would be unable to continue to look after their spouse as they deteriorate and their health declines,

Participant 1: *" .. I know that I can't cope much longer and that she will need care but it will be an awful wrench."*

Participant 5: *" I think the future is a bit of fear with how far [name of husband] will travel down the road of Alzheimer's"*

Participant 9: *"...I'm not worrying about myself but I am wearing out"*

5. (b) Entrapment

Several participants described how they felt a sense of entrapment, of wanting to escape the situation but being unable to do so because of a sense of responsibility.

Participant 3 “...*I could walk out of here and never look back*”

Participant 6: “...*most of the time I’m okay but then there are times when you think you can’t cope and just want to walk away*”

Participant 8: “*I think I don’t want this, I don’t want this but I have to*”

For one individual the sense of entrapment was so strong that she described how she felt if her life had ended.

Participant 5: “...*strangulation is a funny word but it keeps cropping up in my mind.. I now haven’t got a life although I am alive and I do everything*”

And for another participant the sense of feeling trapped was also reflected in a feeling that her life was ‘on hold’.

Participant 6: “your whole life is on hold, can’t see the other side of it.....Am I going to have a life after this?”

5 (c) Guilt and regret

Several of the participants talked of feeling guilty or regretful for losing their temper or getting frustrated during caring activities, not being as open and honest as they had been in the past and also for using respite services.

Participant 7: “*you know you let fly occasionally... erm usually regret it afterwards*”

Participant 3 “ .. *it made me feel terribly guilty because it was, I mean as far as, I've certainly not lied to him as far as I can remember ever erm and I don't think he has to me and I feel as if I am lying to him*”

Participant 1: “*I wouldn't want to see her look of reproach in her eyes if she knew I was putting her in a care home*”

Participant 2: “.. *the first time I went away I felt disloyal*”

Another carer described how felt he was being punished for something he had not done.

Participant 8: “.... *I feel as if I have done something wicked in my lifetime and I'm being punished for it*”

5 (d) Sadness/loss

Four out of the ten participants described how at times they were aware of a sense of loss and felt ‘sad’ or ‘down’ and they all reported coping with this dysphoria by avoiding time to reflect.

Participant 1: “*she was a very, very lively person. it's very sad to see how she,.. how an illness can change a person.*”

Participant 4: “*it's a tragedy how he was to how he's become and it's so sad and er that touches me*”

Participant 8: “*I get down a bit at times, but I just have to carry on*”

5(e) Sense of achievement

Five carers spoke of a sense of achievement when they considered that they were fulfilling their responsibilities in relation to caring or were maintaining their independence e.g.

Participant 7: described how she felt pleased if she managed to get through the day without any problems and if she felt that her husband was happy *“I’m just happy if things are going well and I’ve achieved what I wanted to during the day”* and *“I’m happy if he’s happy”*.

Participant 2: *“I’m still fulfilling my role as a husband”*

Participant 4: *“I like to be an independent person”*

5 (f) Reciprocated Affection

Finally two individuals spoke of feeling that their care and affection was being reciprocated.

Participant 9: whilst talking about still feeling close to his wife *“I’m sure that’s reciprocal even if she can’t come out with it”*

Participant 1: *“.. these playful moments make me see how much she depends on me and how much she cares for me and I care for her”*.

DISCUSSION

This research explored spouse carers' experience of their marital relationship with their husband or wife as they care for them at home in the later stages of a dementia. A number of themes were identified which further our understanding of how carers experience their relationship during this period and these are now considered in the light of the existing literature.

Of note is that almost everybody who was invited to take part in the study consented, often willingly giving up their own free time whilst their spouse was receiving respite care. Several participants spontaneously commented that they had found it helpful to talk about and reflect on their marital relationship. This may be the result of unintentional sample biasing by staff who assisted in the recruitment process, but may also be indicative of the perceived salience of marital relationship factors to spouse carers (a finding that has emerged in earlier qualitative research which has explored the experiences of husbands caring for their wives with dementia Siriopoulos et. al., 1999).

Participants were able to recall their story of meeting their spouse and the establishment of a relationship. For some there was an initial attraction, but the bedrock of the development of a relationship and its maintenance lay in factors such as identifying similar social backgrounds, shared interests, compatible personalities, a sense of partnership and for some a sense of a shared identity as a couple.

Spouses talked of a positive relationship with their spouse prior to the dementia and most had difficulty recalling any aspects of their relationship which made them feel less close as a couple. This again could be the result of sampling bias, resulting in only those who considered themselves to have had a close relationship being willing to take part. However recent research by O'Rourke & Wenaus (1998) suggests that older spouse carers of PWD may typically display a distinct response style that discounts negative perceptions of marital history and conveys 'an inordinately positive appraisal of their spouse and marriage' (O' Rourke & Wenaus, p 385) in order to attain a belief in long term relationship balance or equity and to reduce any cognitive dissonance.

All participants reported how dementia had negatively impacted on their relationship, rendering it an unequal partnership i.e. without mutual exchange of support. However, all carers appeared committed to continuing in the their role describing how they felt that they were repaying past efforts of their spouse in caring for them and/or how they believed their spouse would have cared for them had the situation been reversed.

Baikie (2002) suggests that this can be explained by social exchange theory (which proposes that individuals seek relationships with maximum rewards at the lowest cost and that relationships overall tend to have roughly even outcomes for both partners), and equity theory (which suggests that individuals make contributions to a relationship in proportion to the benefits received and are discomforted by perceived inequity). Using these theories Baikie (2002) proposed that the rewards and costs may not necessarily be in balance all the

time and suggested that spouses report a continued desire to care based on the experience of a good pre-morbid marital relationship where rewards were balanced.

Another theory which has been postulated to account for why individuals continue to care when there is inequity in the relationship is the theory of Communal Relationships (Clark & Mills 1979). Communal relationships are characterised by partners being attentive to each other's needs, whereas less communal relationships are characterised by fewer feelings of responsibility for the other's welfare and being less attentive to the other's needs. Williamson & Shultz (1998) suggest that in historically communal marriages, providing care is an extension of previous relationship style with carers continuing to meet their spouse's needs as they arise, knowing that their partner would have done the same if the need had arisen. This is evidenced in this research with some participants reporting a sense of responsibility for meeting the needs of their spouses and an expressed belief of some that they are the people best placed to understand and meet their needs.

Six participants described how the dementia had led to the 'social death' or 'psychosocial death' of their spouse where the 'psychological essence, individual personality, or self is perceived as dead, though the person remains biologically alive' (Doka and Aber 2002 cited in Doka, 2004 p142). This phenomenon has been identified in previous research on the experiences of mixed samples of carers in terms of their relationship to the PWD, for example Sweeting & Gilhooley (1997) and Adams & Sanders (2004), with the latter study suggesting that this phenomenon is more prevalent in those carers who

are looking after PWD in the advanced stages of cognitive decline. However, this current study has shown that this is not an experience spontaneously described by all those caring for somebody in the later stages of dementia.

Importantly, carers who reported feeling that their spouse had in some ways 'died', continued searching for contrary evidence e.g. continuing to look for a response especially signs of pleasure, or behaving in ways that were counter-intuitive to this belief through maintaining the same routines and interactions, continuing to 'discuss' problems with their spouse who could no longer speak or indeed make any form of response to what was being said, and continuing to plan holidays despite knowing that this would be problematic to the PWD and themselves. In addition eight out of the ten participants spoke of remembering the positive past either in terms of the sort of person their spouse was or the activities they engaged in e.g. Participant 7 "I know he was a very gentle person" and Participant 1 "we had a lot of happy times together, a lot of pleasure together".

One way of construing this is in accordance with cognitive dissonance theory (for a recent review see Draycott & Dabbs, 1998) where caring for somebody who is believed to be 'dead' would be expected to result in cognitive dissonance which would then be reduced by seeking evidence to the contrary i.e. that their spouse is recognisable and alive.

More recent bereavement research may also be helpful in explaining these findings. This research proposes that ongoing attachment to the deceased is an integral part of successful adaptation to bereavement. Thus, the purpose of grief is no longer seen as severing the bonds between living and dead, but to

use ongoing attachment ('continuing bonds') to foster continuity of identity, reinforce coping efforts and provide comfort and support during transition to a new life (Bonnano & Kaltman, 1999).

These 'continuing bonds' are described in the literature as 'inner representations' of the deceased or relationship with the deceased, or ways in which the bereaved remember, internalise and maintain continued psychological involvement with the deceased (Rubin, 1999). A number of continuing bonds have been described in the literature and are reflected in the experiences of the participants in this study. For example, a sense of presence of the loved one, evoking memories about the deceased (Shuchter & Zisook, 1993) and asking for guidance on specific tasks (Silverman & Nickman 1996).

Conversely another way of interpreting this is that carers are being challenged by their role to consider when it is meaningful to say that a person begins or ceases to exist. These are philosophical questions which have been debated by a number of philosophers over many years, and the course of this thinking has been usefully recently expounded by Mathews (2006). Drawing upon the work of Locke (1964), Parfit (1984) and Merleau-Ponty (1965) in particular, Mathews concludes that whilst there has been a privileging of the notion that personhood is dependent upon continued self consciousness (thereby surrendering those suffering from advanced dementia to a state of non-existence), there is cause to view a person as a 'body-subject' i.e. 'neither simply a piece of biological machinery, nor a pure consciousness, but a unity of the two: a consciousness that expresses itself through bodily activity...'

(Mathews, 2006 p.173). Therefore for those carers looking after people with the most severe dementia, those elements of the person which are not conscious or explicit (e.g. anything that is due to genetic influences or more importantly perhaps anything that perhaps was once available to reflection and the consciousness but has now become 'habits') remain the same, and at some level are recognised and may be responded to as core elements of the identity of the person they knew before dementia.

Another important means by which carers in this study were enabled to continue to feel a sense of connectedness or closeness with their spouse was to position responsibility for perceived changes in their spouse's personality or behaviour within the dementia. However, this was not something which seemed to come naturally, at least earlier on in caring for their spouse, and carers spoke of a need to have time to reflect and reframe experiences. Implicit within this was the notion of a belief in their increased competence in caring for their partner. Interestingly, previous research by Graham et. al., (1997), supports this finding and suggests that carers with a greater knowledge about dementia are more likely to have reduced expectation of their dependant's abilities and are more likely to feel confident and competent in their ability as carers. Furthermore, those carers who had a better knowledge about dementia were significantly less depressed but conversely those with a better knowledge of dementia were also more anxious. Clearly there are different ways of interpreting this particular finding. For example, it may be that more anxious carers are more likely to seek out information or/and that more information engenders anxiety. What is clear from this present study however, is that some carers who are attempting to acknowledge the impact of dementia

on their spouse report being 'afraid' or anxious about how far their spouse 'will travel down the road of dementia' and being no longer able to meet the care demands of their spouse within their own resources.

When asked to reflect upon how their marital relationship affected their current wellbeing, carers often became distressed and reported mainly negative impacts on their affect status. Thus, in addition to fear, carers also reported feelings of entrapment, guilt and regret, sadness ('feeling down') and loss.

There is of course abundant evidence in the literature associating depressive symptomatology and depression with caring for somebody with dementia. For example Schulz, et. al.(1995), reviewed the literature in relation to carers of people with dementia and found that almost without exception, studies reported higher levels of depressive symptomatology among carers with one third to a half of all carers suffering from recognisable symptoms. A recent review by Cuipers' (2005), confirmed that the prevalence and incidence of depressive disorders are increased in carers and mirror the prevalence rates for depression in the general population, in terms of gender differences with a higher prevalence rate for women, and there is some evidence that care giving wives more likely to be depressed than care giving husbands (Beeson, et. al. [2000], and Alsphaugh et. al. [1999]).

Carers spoke of sometimes of feeling guilty for concealing the truth from their spouse and for accepting respite services and at times of wanting to 'walk away' which resonates with Pearlin, et.al.'s (1990) theme of role captivity which they postulated is an important element of depression in carers of PWD.

Furthermore, support for this view has emerged from recent research by Martin et. al., (2006) which demonstrated that entrapment was significantly associated with depression, and that experiences of shame relating to self criticism, other peoples expectations and fear of their criticism were significantly related to depression, entrapment and guilt. Interestingly however, guilt (fears of harming others, of letting people down and sense of responsibility) was neither associated with depression or entrapment.

Running alongside this research on depression are also a couple of studies which propose that it may be more meaningful to view some of the negative affect as reflecting `anticipatory grief' (Collins et.al., 1993 and Walker & Pomeroy, 1996), and certainly for some of the carers in this study the sadness they describe could be interpreted as a sign of grieving for the person they once knew e.g. Participant 4, "it's a tragedy how he was to how he's become and it's so sad it touches me" and Participant 1 "she was a very lively person it's very sad to see how she, how an illness can change somebody".

Finally, in addition to the various negative impacts on their wellbeing carers did mention some positives aspects of their caring situation. In particular references were made to a feeling of job satisfaction, a feeling of fulfilment of a sense of duty, and continued reciprocity and mutual affection. Whilst other previous research related to carers of PWD has identified these potential `gains' or sources of satisfaction associated with caring (e.g. Farran et.al, 1991 and Murray et. al., 1999), little is still known about the positive dimensions of caring and their effects on wellbeing, and further research is required to redress the imbalance of knowledge.

Clinical Implications:

Individual autonomy is privileged in Western society and as Hellstrom et. al., (2005) point out, the focus on the *individual* and *their* needs has been formalised recently in health care policy for example the government plans for a New NHS (Department of Health, 1997) and the NSF for Older People (Department of Health, 2001). However, there is now a growing acknowledgement that personhood is constructed and maintained in the context of a relationship Kitwood (1990) and Kitwood (1993) and that. ' So much of personal identity belongs not to self reflection but to the mutual recognition between two people' Oppenheimer (2006 p.200). For older people it is conceivable that their marriage represents 'the single most influential and sustained relationship in their lives' (Beeson, 2003, p.137), and most important source of validation and self referent knowledge. The importance of the marital relationship in understanding and indeed potentially addressing the needs of spouse carers has largely been ignored by research to date and it is not clear how much attention this aspect is afforded in clinical work. Arising from this study are a number of recommendations for clinical practice.

Firstly professional and indeed staff working in voluntary agencies (e.g. Alzheimer's Society) need to be cognisant of the significance of the marital relationship for spouse carers into the latter stages of the caring career. They need to be willing to explore marital relationship with carers (and indeed where possible with PWD) in order to understand their experiences and to find out how best to support them, not only as individuals but also as a couple. This is

especially important for those carers who define themselves as a 'spouse' rather than 'carer' or who have a strong 'couple' identity.

Secondly, it is important to allow carers an opportunity to voice their experience of loss including the pseudo-death or social death of their spouse, without fear of censure. For some carers it may be appropriate to help them articulate and consider the associated philosophical debate about when it is meaningful for them to think of somebody, in this instance their spouse, beginning or ceasing to be a person. However, in order for staff to be able to do this competently and comfortably with carers it is asserted they need first to explore their own thoughts about this philosophical issue, and to be able to access supervision to enable them to hold a non-directive or judgemental stance and to reflect on their practice. This is perhaps especially relevant for those staff who have been socialised or trained in the 'new culture' of dementia care (Kitwood & Benson, 1995) where there is frank acceptance of the notion of personhood and where interpersonal interactions (acts of commission or omission) which can be regarded as potential insults to the persons unique identity and worth as a human being (e.g. the tendency of some people to relate to PWD as though they are an inanimate object or 'dead') are challenged.

Thirdly, it is also important to allow carers to explore ways in which they are attempting to maintain a sense of connection or bond with their spouse and to support them in these endeavours if possible. For example, it may be appropriate to look at ways in which the couple's established routines can be supported, provide information on the effects of dementia (considering making

this specific to the individual rather than generalised information which may lead to increased anxiety about the future) and ways in which they can maximise communication and the sense of 'being with' their spouse. This might include a spectrum of support from the provision of information on strategies to optimise memory functioning and conversation through to advice on how to cope and maintain contact through pre-expressive behaviour based on the principles of Validation Therapy (Feil, 1992) and Pre- Therapy (Morton, 1999, Prouty, 1976, and van Werde, 1994).

Methodological Issues and Ideas for Future Research

A number of limitations can be identified in relation to this research. With regard to the sample, all participants in this study were white British in origin and essentially represented just one cohort. The experiences shared can thereby only be assumed to be relevant for this cultural and cohort group, as it is reasonable to anticipate that expectations and beliefs about marriage are both culturally and cohort sensitive. Participants were drawn from secondary mental health services (thereby most likely representing those presenting with greatest distress and/or need for assistance from formal care agencies), and as this study did not use a measure of depression or distress to contextualise the sample, caution should be exercised in the interpretation of results. In addition, all participants reported that the relationship they were describing had been their only experience of marriage which had endured for many years and there is some research evidence to suggest that the experience of caring may differ for those who have experienced two or more marriages (Krammer, 1993).

No participants were caring for somebody with early onset dementia and whilst the Mini-Mental State Examination (MMSE, Folstein et. al., 1975) was used to identify those spouses caring for a PWD in the advanced stages of dementia, there was still a large variation in terms of presentation of the PWD, with some spouses providing what could perhaps be termed 'end of life' nursing care and others caring for spouses who were still mobile and displaying challenging 'excessive' behaviours e.g. physical aggression. Future research addressing the experiences of carers providing assistance to individuals in the later stages of dementia may wish to consider using a more strictly homogeneous sample as again there is evidence that carers report differential effects of passive and excessive behaviours on the quality of the marital relationship with passive behaviours which diminish the amount of reciprocity of the interactions between partners having the greatest deleterious effect (de Vught et. al., 2003).

In respect to data analysis, data from both husbands and wives was analysed together, on the assumption that the key factors in terms of securing homogeneity of the sample was community co-habitation and dementia severity. Although there were no obvious or striking differences in husband and wives experiences noted within this study, there is some evidence from previous studies that husband carers may experience and respond to caring differently to wife carers. For example McFarland & Sanders, (1999) demonstrated that husbands tend to concentrate more on problem solving and the provision of concrete or practical care giving tasks and to minimise their

emotional reactions to caring. Therefore future research may wish to factor in gender when identifying a sample.

A role for further research would be to explore spouses' (and PWD) experiences of their relationship throughout the care trajectory i.e. to conduct longitudinal studies. This would provide insights into how the relationship maintains or alters and may also provide information on differences between those carers who continue to look after their spouse at home and those who seek fulltime care. In addition, future studies are required in order to understand the circumstances under which spouse carers report the phenomenon of 'social death', and their experiences of it, in particular their understanding of when they believe that their spouse ceases to exist as they person they once knew. In parallel with this is the need for research to further clarify from the carers' perspective the meaning and functions of their attempts to sustain a relationship whilst they at the same time, report the belief that their relationship with their spouse has ended or that the person they knew as their spouse has died, and following on from, this how support agencies can be of assistance.

CONCLUSION

This research is unique in that it comprises a qualitative study of carers' experience of their marital relationship as they care for their spouse in the latter stages of dementia. It confirms the importance of viewing carers' experience of providing care to their spouse with advanced dementia in the

context of past, present and potentially future relationship. It also offers important insights into how carers perceive their relationship to have changed as a result of dementia, their desire to continue caring, the impact on their wellbeing and their attempts to try to sustain a relationship with their spouse whilst at the same time reporting a sense of loss of the relationship or the person they once knew. Clinical implications are discussed and a detailed critique of the methodology plus ideas for future research studies are outlined.

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SECTION THREE

CRITICAL REFLECTION ON THE RESEARCH PROCESS

CRITICAL REFLECTION ON THE RESEARCH PROCESS

CONTENTS:

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CRITICAL REFLECTION ON THE RESEARCH PROCESS

This section provides a reflective account on the process of conducting the research. It is organised into the following sections; Origins of the Research, Implementation of the Research Including Key Learning Points, Plans for Dissemination of Research Findings, and finally, Continuing Professional Development Needs in Relation to Conducting Research.

Origins of the Research

There were two main contextual influences for this research. The first was the researcher's post qualification clinical experience of working in Mental Health Services for Older People. The second, created through a major organisational restructuring which impacted on the researcher's job role and responsibilities, was the opportunity to register for a Post Qualification Doctoral Degree.

In addition to these contextual factors were two other guiding experiences.

The first was attendance at a locally organised training event for Clinical Psychology Supervisors on recent advances in bereavement research and its clinical applications. Loss and bereavement are often core issues to clinical practice with an older client population and this day was extremely helpful in updating knowledge of the evidence base and its application in this area, in particular the move away from a staged model of grief to a continuing bonds model. The final issue which brought these other factors together in the form of a research question was a clinical referral. This referral was for a

psychological assessment of a gentleman with severe dementia who had been admitted to a hospital inpatient area as a result of frequent and serious aggressive behaviours. As an integral part of the assessment the author asked for information on his life history from his wife. During the interview the gentleman's wife described how she felt that her marriage was over and that her husband had died leaving behind only a physical representation. At the same time however she reported behaving in ways which appeared to be contrary to these beliefs. For example, she said she continued to visit every day and tried to engage him in conversation hoping to receive confirmation that he recognised her. In addition she took small amounts of what had been his favourite food and drinks into the ward and talked about when he might be able to return home. The researcher thereby became interested in and wanted to use the opportunity, to research how carers looking after a spouse with severe dementia experience their marital relationship, and whether and how they feel this influences their ability to care and their wellbeing.

Implementation of the Research Including Key Learning Points

The opportunity to engage in this significant Continuing Professional Development programme including this research project was initially created through organisation change. However staff changes only two weeks following the researcher's registration for study, coupled with repeated and ongoing organisational restructuring have ironically proved to be the single most pervasive threat to its completion. More specifically, as the configuration and responsibilities of the researcher have continued to change, there has been increasingly pressure on work time. This has led to the researcher perceiving

growing tension between their individual professional aims and the demands of fulfilling their role within the organisation. The result of this has been that most of the study has taken place in the researcher's own time.

Thus one of the key learning points for the researcher, is that whilst it was relatively easy to maintain personal motivation for study and continuing professional development, it was nevertheless, extremely difficult to maintain momentum for research whilst employed in a busy clinical and managerial post. This seems to be particularly challenging when there is such instability within an employing organisation.

A potential future solution to this would be to negotiate a job plan where there is protected time available alongside an organisational commitment to honour this, irrespective of changing roles and responsibilities. However it is asserted that further education and cultural change regarding the value of this type of research (in contrast to the more readily appreciated small scale service evaluation studies) would initially be required within the organisation.

Moreover, it would be necessary for the organisation to acknowledge the research contribution of psychologists in order for them to view research time as a legitimate, valued and prioritised component of their job role and responsibilities.

In addition to restructuring within the researcher's employing organisation, changes within the University and for the original 'field' supervisor resulted in the need to identify two new supervisors during the study period. Although this transition was difficult for the researcher and no doubt for the supervisors who

had to absorb the work of supervising another student, their encouragement and support throughout the refinement and development of the research project and also during analysis and write up has enabled the researcher to sustain motivation and to complete this study. In addition to their research expertise, their willingness to listen, reflect and to assist the researcher by supporting them through the process of acknowledging and challenging biases and assumptions about the research phenomenon in order to reach new understandings (i.e. to have 'reflexive validity', Stiles, 1993) was welcomed and appreciated.

Support was also received from individuals (employed staff and carers) from the local branch of the Alzheimer's Society (who offered their opinion and advice on the research protocol), from within the employing organisation's Research Department (who were able to provide invaluable expert guidance in the preparation of submissions to local Ethics and Governance Committees) and colleagues from Community Mental Health Teams (who assisted in the recruitment of the participants). There is no doubt that these long established relationships and networks led to key people's engagement with the researcher in facilitating this research, and served as a reminder of how important the role of a 'field' or clinical supervisor is for Clinical Psychology Trainees.

It is also acknowledged how accommodating and supportive the carers of PWD have been in the implementation of the research study. The majority of those approached by the Community Mental Health Teams (CMHTs) consented to take part sometimes giving up precious respite time to

accommodate the need of the researcher to interview them without the presence of their spouse. Although it is possible that the CMHTs inadvertently screened out those who they felt were more likely to decline to participate, when the high positive response rate was discussed with the CMHTs after data collection, this is not what they reported.

Another interpretation is that carers perceived the research as providing a positive opportunity to privately and confidentially explore their marital relationship with facilitation from an independent person. Certainly when asked for feedback on the research process, some carers described how they had found it useful to have the time and opportunity to reflect on and discuss their marital relationship with somebody else. During the research interview attempts had been made to reflect, summarise and check the accuracy of the researcher's interpretations, however no provision had been made within the protocol for consulting again with the participants towards the end of the analysis in order to ensure that the interpretations were meaningful to them (Mays & Pope, 2000). On reflection, adding this stage into future research projects may not only provide an additional validity check and quality control measure for the research, but may also be appreciated by the research participants and would therefore be considered by the researcher.

During the interviews the author became more cognisant of the difference between a clinical interview and a research interview. Whilst it was necessary to provide information, reassurance and emotional support at times during the interviews it was also important to establish boundaries as a researcher interested in gaining a better understanding of their experience rather than as

a clinical psychologist offering advice or therapy as part of the CMHTs. That is, to provide 'empathic neutrality' where there is empathic engagement with the information shared but also neutrality in relation to the actual content (Patton 1990). This initially felt alien to the researcher, and was a topic discussed both within supervision and also informally with other colleagues who were experienced in using qualitative methodologies. However having recognised and validated the initial discomfort, it then became more easily dealt with by the researcher within the interviews by taking care to explain their role during introductions and also by asking participants to reflect on the process of taking part in the research at the end. In addition it also led the author to become more aware of the potential value of arranging regular debriefing opportunities and possibly peer-group supervision for future research projects (Tanji, 1999).

Another difference which became apparent during the interviews was the need to collect all the information during a single interview, rather than over a more flexible assessment period. The researcher was aware that some of the information being shared was of a highly sensitive and emotive nature and that participants may have been 'less open to sharing their experiences without having a sense of trust and knowledge that their vulnerability is of concern to the researcher and a feeling that they are respected as individuals' (Cowles, 1988, p171). It was also the case that the researcher was aware that whilst the participants had agreed to take part in the study it could not be entirely predicted what it would uncover and there was a need to maintain choice for participants throughout the research process (Smith, 1992).

This called for the researcher to a) maintain empathic neutrality for what was being discussed, b) employ active listening skills (attending to non-verbal as well verbal communication), c) provide sufficient structure for the interview to ensure the topics identified by the research question were covered, whilst allowing participants to elaborate on the themes which were of importance to them (thus allowing the emergence of new themes), and d) remain vigilant for indications of the acceptability of the research interview.

The more familiar the researcher became with the topic guide and more experience of conducting the interviews with different participants the easier this became. However, it was acknowledged that whilst the research interviews were interesting and varied, conducting them was tiring and required good preparation and the discipline to create field notes after the interview in order to capture the researcher's reflections. It also highlighted the importance of making time to carry out pilot interviews and to listen carefully to the audiotapes of these pilot interviews in order to increase skills in interviewing.

An opportunity to further reflect on the process of the interviews and the interpretation and analysis of the data was afforded during the three way discussions with the researcher's supervisors following independent coding of transcripts which occurred as part of the quality control. Through a detailed discussion the researcher was able to explore similarities in the codings used by themselves and the supervisors and examine any differences. This facilitated systematic validation and challenge of the researcher's interpretations to occur and encouraged a greater awareness of the possible

influences of the researcher's own perspective and the language used in the analysis and write up of the research. For example, during initial coding the researcher had identified a theme which related to carers' reflections on their past relationship and shared history together. Initially the researcher had termed this as 'reverence for the past' however through discussion with the two supervisors and close examination of the actual transcripts, whilst there was general agreement of this theme it was agreed that this could be more accurately described as 'honouring the past'.

One final key learning point for the researcher has been the additional challenge of preparing the thesis in the style of manuscripts for submission to journals. This challenge was amplified by the researcher having to wrestle with complying with instructions for contributors for the chosen target journal (Aging and Mental Health) whilst adopting the university word limits (which are significantly in excess of the journal word limits) and the need to write an abstract in the form requested by another journal (British Journal of Clinical Psychology). The difficulties of integrating these instructions have been further exaggerated by the instructions for contributors to the journal Aging and Mental Health effectively denying the researcher access to their usual systems for helping to orientate the reader to the contents of documents through the use of differentiated headings and subheadings (e.g. though the use of numbering, indentation and type face). However having undergone this process once, it is anticipated that future drafts prepared with only one set of instructions with the aim of submission to a journal will be easier.

Plans for Dissemination of Research Findings

Several participants commented that one of their reasons for taking part in the research was the hope that their involvement may be of assistance in educating professionals supporting carers of PWD in the future. This acts as an additional incentive to the researcher to share the research findings as a way of ensuring that the participants' wish to help others is honoured as far as possible. In the first instance (ideally in spring through to the autumn 2008) it is envisaged that the main findings will be shared with the host Trust through the established formal research feedback system. In addition it is also felt to be appropriate to use a number of less formal networks and mechanisms to share the findings. This includes writing a short article for the Trust's newsletter on carer issues for staff and carers, presentations to CMHTs at practice development groups and Psychology Older Peoples Services Speciality Meetings. Following this it is also envisaged that a presentation will be offered to the local Psychologists' Special Interest Group Working with Older People (PSIGE) and the local branch of the Alzheimer's Society. (Obviously considerable thought and care will need to be employed when preparing feedback for the Alzheimer's Society audience in order to ensure that anonymity of participants is maintained, and also that the potentially controversial and emotive content is appropriately and sensitively handled. It may also be appropriate to seek the advice of the branch Co-ordinator and to use opportunities to elicit the views of staff within the Trust and also other psychologists specialising in working with older people within the region whilst preparing this feedback.)

Finally in order to disseminate the findings as wide as possible both the literature review and the research report will be redrafted in the autumn of 2008 with the aim of submitting these separately to the journal Aging and Mental Health. In addition during December 2008 it is anticipated that a paper will be offered for the PSIGE national conference in 2009.

Continuing Professional Development Needs in Relation to Conducting Research.

This research was the first study the researcher has embarked upon using qualitative methodology and without doubt this has posed a steep learning curve. Despite the difficulties in securing the necessary time to conduct the research within work responsibilities, the researcher has on balance enjoyed the research process and developing skills in this methodology. However, this has marked the beginning rather the end of learning and there still exists a need to become better acquainted with the implementation of qualitative research methodologies.

Formal learning opportunities in the form of conferences and workshops will be sought and in addition, it is anticipated that the researcher will make use of a range of potentially more readily available informal opportunities. For example, it may be possible to attend research networks within and outside the Trust, to make opportunities to discuss methodologies and research processes with other psychologists conducting research especially in Older Peoples Services, and to read relevant papers and books. In addition, having become more familiar with these methodologies and with the formal governance and ethical

approval systems, the researcher would feel more confident in offering 'field' supervision for Trainee Clinical Psychologists' (and other staff's) research projects and would see this as a positive contribution to their own CPD.

Finally, the possibility of conducting further research studies is currently being actively explored. Realistically, given the very real pressures on the researcher's time at present, it is anticipated that this will need to be a joint study with another member of staff. However the researcher is looking forward to this as a further complimentary learning experience in conducting research.

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SECTION 4: APPENDICES

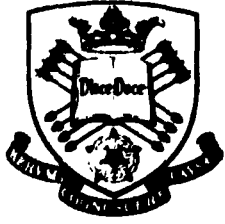
SECTION 4: APPENDICES

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Appendix 1: Guidance For Contributors To The Journal Aging Mental Health
And Letter Of Approval From The Research Tutor



The
University
Of
Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

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12 November 2007

Petrina Brown
Clinical Psychology Unit
University of Sheffield

Dear Petrina

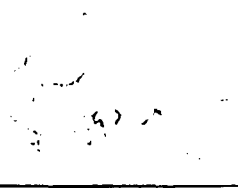
I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Aging and Mental Health

Research Report: Aging and Mental Health

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely


Zaffer Iqbal
Research Tutor

AGING MENTAL HEALTH

Editors: Martin W. Orrell & Dan G. Blazer

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137

AGING & MENTAL HEALTH

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Aging & Mental Health provides a forum for the rapidly expanding field which investigates the relationship between the aging process and mental health. It addresses the mental changes associated with normal and abnormal or pathological aging, as well as the psychological and psychiatric problems of the aging population. The journal covers the biological, psychological and social aspects of aging as they relate to mental health. In particular it encourages an integrated approach between the various biopsychosocial processes and etiological factors associated with psychological changes in the elderly. It also emphasizes the various strategies, therapies and services which may be directed at improving the mental health of the elderly. In this way the journal has a strong alliance between the theoretical, experimental and applied sciences across a range of issues affecting mental health and aging. The journal provides as original and dynamic focus to help integrate the normal and abnormal aspects of mental health in aging. In addition, theoretical issues can be set in the context of the important new practical developments in this field.

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Notes for Contributors

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All submissions should be in the style of the *Publication Manual of the American Psychological Association* (4th edition, 1994). Papers should be typed on one side of the paper, double spaced throughout (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

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The text should normally be divided into sections with the headings, Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

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References should be listed at the end of the paper in alphabetical order, typed in double spacing. Responsibility for the references and their verification against the original documents lies with the author(s).

References should be listed on a separate sheet(s) in the following standard form, capitalization and punctuation:

(a) for periodical articles (titles of journals should not be abbreviated):

Woods, B. (1995). Dementia care: progress and prospects. *Journal of Mental Health*, 5, 115–124.

(b) for books:

Norman, A. (1987). *Aspects of ageism*. London: Centre for Policy on Ageing.

(c) for chapters within multi-authored books:

Robertson, I.T. (1994). Personality and personnel selection. In: C.L. Cooper & D.M. Rousseau (Eds.), *Trends in organizational behavior* (pp. 75–89). Chichester: Wiley.

Units of measurement

All measurements must be cited in SI units.

Illustrations

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted on a separate sheet of paper, numbered on the back with Figure number (Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate sheet, should include keys to symbols, and should make interpretation possible without reference to the text.

Figures should ideally be professionally drawn and designed with the format of the journal (A4 portrait, 297 × 210 mm) in mind and should be capable of reduction.

Tables

Tables should be submitted on separate sheets, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

Proofs

Proofs will be sent to the author nominated for correspondence by email. Proofs are supplied for checking and making essential typographical corrections, not for general revision or alteration. Proofs should be printed out, corrected and returned (by air mail or fax if overseas) within 72 hours of receipt.

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Appendix 2: Ethical/Governance Approvals



Derbyshire Research Ethics Committee

3rd Floor
Laurie House
Colyear Street
Derby
DE1 1LJ

Telephone: 01332 868765

Facsimile: 01332 868785

22 March 2007

Ms P S Brown
Head of Older Peoples Psychology Services
Derbyshire Mental Health Services NHS Trust
Oaklands
103 Duffield Road
Derby
DE22 1AE

Dear Ms Brown

Full title of study: CARING FOR A HUSBAND OR WIFE WITH DEMENTIA -
AN EXPLORATION OF CARERS' EXPERIENCE OF THEIR
RELATIONSHIP

REC reference number: 07/Q2401/20

Thank you for your letter of 17 March 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Continued/

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		22 January 2007
Investigator CV		16 January 2007
Protocol	2	March 2007
Covering Letter		19 January 2007
Summary/Synopsis – research timetable	2	March 2007
Letter from Sponsor		20 December 2006
Peer Review		19 September 2006
Interview Schedules/Topic Guides - Structured	2	March 2007
Interview Schedules/Topic Guides - Semi-structured	2	March 2007
Participant Information Sheet: Spouse	2	March 2007
Participant Information Sheet: Community Mental Health Team Members	2	March 2007
Participant Consent Form: Spouse	2	March 2007
Response to Request for Further Information		17 March 2007
Response to peer review		06 November 2006
Academic Supervisor's CV		
Costing Form	2	March 2007
Confidentiality Form	2	March 2007
Consent to contact	2	March 2007

R&D approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final approval from the R&D office for the relevant NHS care organisation.

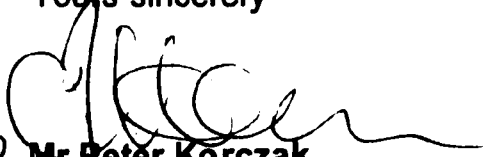
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q2401/20	Please quote this number on all correspondence
-------------	------------------------------------------------

With the Committee's best wishes for the success of this project

Yours sincerely

pp 
Mr Peter Korczak
Chairman

Email: jenny.hancock@derwentsharedservices.nhs.uk


Enclosures:

Standard approval
 Site approval form

Copy to:

Dr Andrew Thompson
Clinical Psychology Unit,
Dept of Psychology
Sheffield University
Western Bank
Sheffield
S10 2TP

Corinne Gayle
Research Co-ordinator
Derbyshire Mental Health Trust
Kingsway House
Kingsway Hospital

Derbyshire Research Ethics Committee					
LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION					
<i>For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.</i>					
REC reference number:	07/Q2401/20	Issue number:	1	Date of issue:	22 March 2007
Chief Investigator:	Ms P S Brown				
Full title of study:	CARING FOR A HUSBAND OR WIFE WITH DEMENTIA - AN EXPLORATION OF CARERS EXPERIENCE OF THEIR RELATIONSHIP				
<i>This study was given a favourable ethical opinion by Derbyshire Research Ethics Committee on 20 March 2007. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.</i>					
Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes ⁽¹⁾
Ms P.S. Brown	Head of Older Peoples Psychology Services	Derbyshire Mental Health Services NHS Trust	Derbyshire Research Ethics Committee	22/03/2007	
Approved by the Chair on behalf of the REC:					
 (Signature of Co-ordinator)					
..... JENNY HANCOCK (Name)					

(1) The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension or termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.



The
University
Of
Sheffield.

The
Research
Office.

Ms Petrina Brown
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Ms Sarah Fulton
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16th April 2007

Telephone: +44 (0) 114 222 1448
Fax: +44 (0) 114 222 1452
Email: r.j.hudson@sheffield.ac.uk

Project title: Caring for a husband or wife with dementia – an explanation of carers' experience of their relationship
URMS number: 115436

Dear Ms Brown

LETTER TO CONFIRM THAT THE UNIVERSITY OF SHEFFIELD IS THE PROJECT'S RESEARCH GOVERNANCE SPONSOR

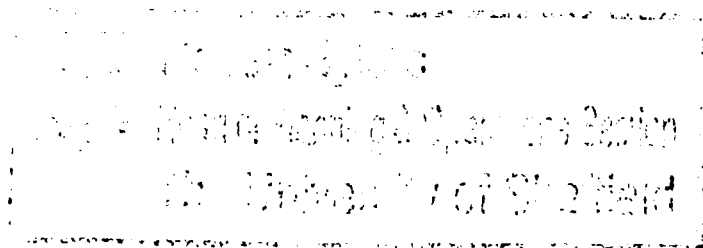
The Research Office has reviewed the following documents:

1. A University approved URMS costing record;
2. Signed, dated confirmation of independent scientific approval;
3. Signed, dated confirmation of ethics approval.

All the above documents are in place. Therefore, the University can now **confirm** that it is the project's research governance sponsor and, as research governance sponsor, **authorises** the project to commence research activities. You are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Good Research Practice Standards: www.shef.ac.uk/content/1/c6/03/25/82/collatedGRP.pdf

Your Supervisor, with your support and input, is responsible for monitoring the project on an ongoing basis. Your Head of Department is responsible for independently monitoring the project as appropriate. The project may be audited during or after its lifetime by the University. The monitoring responsibilities are listed in **Annex 1**.

Yours sincerely



cc. Supervisor: Professor Pauline Slade
Head of Department: Professor Richard Eiser

Mental Health Research Unit
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E mail: Corinne.Gale@DerbysMHServices.nhs.uk

4 April 2007

Clinical Psychology Services
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Derby
DE22 1AE

Dear Petrina

RE: Caring for a husband or wife with Dementia – An exploration of carers experience of their relationship

I am writing to inform you that the Derbyshire Mental Health Trust Clinical Research Committee has reviewed and approved the above research protocol, and we have received confirmation of ethical approval.

As part of the dissemination process within the Trust, please can you provide a short summary of your research findings once the study is complete.

If you require any further information please do not hesitate to contact me.

Yours sincerely



Corinne Gale
R & RD Manager

Appendix 3: Information For CMHTs

**INFORMATION FOR COMMUNITY MENTAL HEALTH TEAM
MEMBERS**

**Title of the Project: Caring For a Husband or Wife with Dementia -
An Exploration of carers Experience of Their Relationship**

Name of Researcher: Petrina Brown (Dip Clin Psy, M.A.) Post Graduate Student Sheffield University Doctorate in Clinical Psychology (D Clin Psych)

Dear Team

I recently visited your team meeting to discuss the background and relevance of my research study and to ask for your help in recruiting people to take part. Below is a summary of the information and guidance on criteria for inclusion in the study and how to invite people to take part.

What is the study about and how is it relevant?

During the course of our work carers of people suffering from dementia may explicitly or implicitly talk about they experience their relationship with the person they are caring for and how this influences them in their caring role. This study aims to systematically collect, interpret and eventually through publication, share this information in order that we as professionals can understand how to better support people caring for someone with dementia.

Who is being invited to take part in the study?

I will be asking all CMHT's in the Mental Health Trust to identify carers who may be willing to take part in the study. I will need a maximum of 12 carers who are:

1. looking after somebody with advanced dementia (the sufferer scoring 10 or less on the MMSE)
2. either the husband or wife of the sufferer
3. to be caring for their wife/ husband at home
4. to be fluent in English (due to the nature of the data collection)
5. not suffering from any significant mental illness or degree of distress which might be exacerbated by taking part in the study.

What will be expected of those taking part?

Participants in the study will need to agree to take part in an interview with myself which will be taped and later transcribed to assist analysis.

Interviews:

1. are expected to last no longer than 2 hours
2. need to be conducted in private i.e. without the person with dementia present. (*I would find it helpful if you could help facilitate this by working with me to identify suitable arrangements for care of the person with dementia should this be necessary.*)
3. are confidential and anonymity will be protected (*the exception to this which will be explained to participants is if they indicated during the interview that either the sufferer or themselves are at risk of harm. In these circumstances I would discuss any concerns that I had with them and together decide what additional help they may require and who in the first instance it would be best to inform*).
4. can take place in the persons own home my office (address) or at another mutually convenient location if requested and available.

What will I need to do to assist with this study?

All I need you to do is:

1. Identify carers who are eligible to take part from your caseload
2. Ask them to read the information sheet provided
3. If having read the information sheet they are willing for me personally to contact them to discuss what will be involved in taking part in the study help them complete the form and return it to me. (It is important to note that this consent form is a way of ensuring they are happy for me to contact them to *discuss the possibility of taking part in the study, and does not mean that they have consented to be participants*).
4. Advise me on the local options for providing cover for the carer to enable them to take part in the study and the potential impact on the service user. (For example I anticipate that most sufferers will have contact with other services e.g. day services, sitting services, in which case I may need to liaise with these services in order to provide additional hours to cover the time taken for the carer to be interviewed. In these circumstances it will be necessary for us to consider the potential impact on the wellbeing of the sufferer and to inform their consultant psychiatrist/GP of any arrangements made. If alternative arrangements for care during the interview cannot be arranged without potentially adversely affecting the

sufferer, the carer's offer of involvement will be sensitively declined by the researcher and the reasons behind this decision explained.)

5. Advise me of any risk issues relevant to me visiting the person at home and/or interviewing the person alone and any appropriate risk management plans in operation.

If you have any queries relating to this research in general or with regard to applying the inclusion criteria to any individual please contact me at Tel:

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I appreciate any support you can offer in recruiting participants to take part in this study especially as I am aware that your assistance will inevitably mean the addition of some extra planning, thought and follow-up in what is an already busy schedule. With the help of all the CMHTs I hope that I will be able to gain sufficient carers in a relatively short space of time and I will let you know immediately when we have recruited sufficient participants for the study.

Thank you for your help

Petrina Brown

Clinical Psychologist (Derbyshire Mental Health Services NHS Trust)

Post Graduate Student (University of Sheffield)

Appendix 4: Information Sheet for Participants (Note: Original size reduced for reproduction)

PARTICIPANT INFORMATION SHEET (March 2007, version Two)

**Caring For a Husband or Wife with Dementia
An Exploration of Carers Experience of Their Relationship**

PHOTO
Of
RESEARCHER

My name is Petrina Brown and I am an experienced Clinical Psychologist specialising in working with older people including those suffering from dementia and their carers. I am currently studying for a doctoral qualification and am undertaking a piece of research focussing on the experiences of husband and wife carers of dementia sufferers.

I have asked members of the Community Mental Health Team to pass on this information sheet to individuals like yourself, who are caring for a spouse with dementia, and to ask for your help. Before deciding whether you would like to take part it is important to read the following information carefully and ask questions if you wish.

What is the study about?

An increasing number of people are diagnosed with dementia and are being cared for at home by their relatives and friends. This study has been designed to explore how carers experience their relationship with the person they are caring for and how this influences them in their caring role. It is hoped that information we learn from this study may in due course help professionals understand how to better support people like yourself who are looking after a relative with dementia.

What will be involved if I take part?

It is up to you to decide whether or not you would like to take part in the study. If you do decide to take part you will be asked to sign a consent form and to take part in a single interview with myself lasting no longer than 2 hours. During the interview I will invite you to talk about your experiences of your relationship with your husband or wife. In total I am looking for a maximum of 12 participants.

Will the interview be confidential?

Yes. I will need you to agree to the interview being tape recorded so that I can listen to it over again and to write down (transcribe) what you have said. However I will anonymise the written information so that only I know your identity, and both the tapes and written copies will be kept securely and the tapes will be destroyed when the study is complete. Short extracts or quotations from our conversation may be included in the final report in order to illustrate important parts of the results of the study, but nobody else other than you and I will be able to identify who contributed this information.

Are there any circumstances where confidentiality would be broken?

In line with routine clinical work, the only circumstances where I would have to break confidentiality is if you indicated during the interview that either you or the person you are caring for is at risk of harm. I would of course firstly discuss any concerns that I had with you and together we could decide what additional help you require and who it would be best to inform.

When and where will the interviews take place?

We can arrange a mutually convenient time and I can visit you at home or you could come to my office (I can arrange transport). Although I recognise the practical difficulties of getting time alone, in order for you to be able to talk freely it is best if your husband or wife is not present in the same room during the interview. It may be possible for me to arrange services for example day care or sitting services to cover the time you will be taking part in the interview, and this is something we could discuss if you are happy for me to contact you to discuss the study further.

Will there be any effects on my husband/wife's treatment or the support and help offered to me?

Taking part (or declining to take part) in the study will not affect the treatment offered to your spouse or the services and support you receive in any way.

Can I withdraw from the study at any time?

You do not have to take part in this study. If you do decide to take part you are still free to withdraw at any time and without giving a reason, and any information you have provided me with will be destroyed.

What do I do if I have any complaints about this research?

This study has been given a favourable ethical opinion for conduct in the NHS by the Derbyshire Research Ethics Committee.

However, if you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you and you are not compromised in any way because you have taken part in this study. If you have any complaints in the first instance you can decide to:

- Raise any issues with myself, Petrina Brown on Tel. 01332 292740
- Contact the research supervisor (Prof Pauline Slade at Sheffield University Tel: 0114 2226570)

If this is not satisfactory, you can also decide to use the Trusts Complaints Procedure by contacting (Anne Reilly, Tel: 01332 362221, Trust Headquarters, Bramble House, Kingsway Hospital)

I appreciate the time you have taken to read through this information and would be very grateful if you would allow me to contact you by phone or by arranging to meet with you to discuss whether you would like to take part.

Please see the attached form ...

PARTICIPANT INFORMATION FORM

**Caring For a Husband or Wife with Dementia
An Exploration of Carers Experience of Their Relationship**

I(please print name) am happy for Petrina to contact me to discuss the possibility of taking part in the study about relationships with people who are suffering from dementia.

I can be contacted on

Telephone.....

Name of Community Mental Health Team worker

.....

Please return to:
(Address)

Appendix 5: Consent Form (Note: Original size reduced for reproduction)

Study Number: 07/Q2401/20

Participant No:

CONSENT FORM
(1 for participant, 1 for researcher)

Title of the Project: Caring For a Husband or Wife with Dementia – An Exploration of carers Experience of Their Relationship

Name of Researcher: Petrina Brown (Dip Clin Psy, MA) Post Graduate Student Sheffield University Doctorate in Clinical Psychology (D Clin Psych)

**Please
initial box**

1. I confirm that I have read and understand the information sheet dated March 2007 (version Two) for the above study and have had opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my or my spouse's medical care or legal rights being affected.
3. I understand that relevant sections of any data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust, where this is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I agree to the interview being audio taped.
5. I understand that anonymised direct quotes may be used in the study write up.
6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix 6: Topic Guide

TOPIC GUIDE
(FOR SEMI-STRUCTURED PART OF THE INTERVIEW AFTER BASIC
DEMOGRAPHIC/CONTEXTUALISING INFORMATION HAS BEEN
GATHERED THROUGH STRUCTURED INTERVIEW)

Preamble/introduction to less structured format of the next part of the interview

Description of relationship with X before s/he began suffering from dementia?

Prompts:

The story of meeting and marriage.

- . behaviours/activities which helped you feel close (and endured throughout marriage)
 - . behaviours/activities which made it more difficult to feel close (and endured throughout marriage)
 - . thinking about this enduring relationship with X before s/he developed dementia what parts of it do you think
- (a) help/hinder you in caring for them?
(b) have a positive/negative effect on the way you feel?

Description of relationship with X now

Prompts

The round of daily activities and experiences...

- . How it has changed
 - . behaviours/activities which help you feel close
 - . behaviours/activities which make it more difficult to feel close
- thinking about the relationship with X now what parts of it do you think
- (a) help/hinder you in caring for them?
(b) have a positive/negative effect on the way you feel?

Any additional comments you would like to make?

Check to ensure that participant is feeling okay after the interview

Appendix 7: 'Who Said What' Table

APPENDIX 7: 'WHO SAID WHAT' TABLE

ESTABLISHING CONNECTIONS AND FORMING A LASTING RELATIONSHIP						
	JUST KNOWING	COMPATIBLE PERSONALITY	INTERESTS	SOCIAL BACKGROUND	IDENTITY COUPLE INDIVIDUAL	PARTNERSHIP
1		√	√		√	√
2	√	√	√	√	√	√
3		√	√		√	√
4		√	√	√	√	√
5	√		√	√	√	√
6	√		√		√	√
7	√	√	√	√	√	√
8		√	√	√		√
9		√			√	√
10				√	√	√

APPENDIX 7: 'WHO SAID WHAT' TABLE (CONT)

DEMENTIA AS A THREAT TO RELATIONSHIPS / MAINTAINING THE EXISTENCE OF RELATIONSHIPS						
	DEATH OF A SPOUSE	END OF RELATIONSHIP	SEEKING A RESPONSE	REMEMBERING THE PERSON/RELATIONSHIP	SUSTAINING ROUTINE/INTERACTION	RECOGNISING DEMENTIA
1	√		√	√	√	√
2	√	√	√	√	√	√
3	√		√	√		
4	√		√	√		√
5	√	√	√		√	
6	√	√	√	√	√	√
7		√	√	√	√	√
8			√	√		
9		√	√		√	√
10		√	√	√	√	

APPENDIX 7: 'WHO SAID WHAT' TABLE (CONT)

DESIRE TO CARE					
	RESPONSIBILITY	DUTY	RECIPROCITY	GUILT	HONOURING THE PAST
1	√		√	√	√
2	√		√	√	√
3	√	√	√	√	√
4	√		√		√
5					√
6	√	√	√		√
7	√				√
8	√		√		
9	√		√		√
10	√	√			

APPENDIX 7: 'WHO SAID WHAT' TABLE (CONT)

EXPERIENCING THE IMPACT OF CARING						
	FEAR	ENTRAPMENT	GUILT	SADNESS / LOSS	SENSE OF ACHEIVEMENT	RECIPROCATED AFFECTION
1	√		√	√		√
2			√	√	√	
3		√	√			
4	√			√	√	
5	√	√				
6		√				
7	√		√		√	
8		√	√	√		
9	√			√		√
10						

Appendix 8: Example of Transcript and Analysis

APPENDIX 8: EXCERPTS OF TRANSCRIPT TWO TO SHOW EXAMPLE
OF ANALYSIS

- 925 PB: mm. Thinking about your relationship with [name of wife] now
926 can you tell me a little bit about the activities or behaviours that
927 help you feel close?
928 The one thing I do, I talk, when I meet people I talk a lot about
929 what we did and I'm..Im always, I was always a little bit worried
930 when it first started that people would be thinking you know,
931forget what she'd done
932 PB: mmm?
933 And so anybody new who comes in I make sure that they know
934 what she's done she's been a [name of profession], she's
935 written a book and all this sort of thing and I'm still very proud of
936 what she did so it's still part and parcel of my conversations so
937 that's that's one one way.
938 PB: So remembering and and talking about [name of wife]'s
939 achievements in her life, helps you feel close to her?
940 Partic. 2 Yes it does, and then I buy all her clothes and you know I... I,
941 my daughter helps me sometimes but she's got a different taste
942 to me and er so, but that's.. that's something else I think 'now
943 would [name of wife] like this and would she like that'? And the
944 other thing is I make sure she has the food she has, I make sure
945 I give her the food she used to like.
946 PB: Mm

*remembering
how it used
to be
would people
think this
is how she
was
PB: always
been
embarrassed*

*need for
others to
recognise
who she
was*

*remembering
the person
as they
were*

*continuing
to respect
preference
(past)*

*thinking
what his
wife would
like*

947 Partic. 2: You know all all this sort of thing as though it's a continuation of
 948 *continuing past behaviour* what I did before and er I still.....

949 PB: So you're still thinking about her and respecting her tastes and
 950 preferences?

951 Partic. 2: Yeah

952 PB: Yes

953 Partic. 2: I still talk to her you know if something is worrying me I talk I tell
 954 *treat wife as if she was able to respond* her. I don't think she understands but at least it's.. it's still how I
 955 *no help* would have done if she was still able to respond.

956 PB: Mm hm

957 Partic. 2: That helps. I'm not saying it makes me, at least I decide myself
 958 *'seeking' advice / approval* but it's.. it's er something that I do and er it's er it's a part of my
 959 life talking to her and tell her what I'm doing, what I'm thinking of
 960 doing. Told her about the gardener and I don't know if she'll
 961 approve of that or not, I've not made my mind up. Although she
 962 liked, she liked being, she liked being in the garden she doesn't
 963 know a weed from a plant. She wasn't, she wasn't a gardener.
 964 *thinking about achievement* So I know she used to, she used to come and help me and I'd
 965 say 'No don't that's.. that's a flower, or that's a weed and not a
 966 flower' but I mean when we lived at [another nearby town] we
 967 did all the gardening together we.. er she layed, we layed turf
 968 and that sort of thing. She'd wheel the turf then you know
 969 she'd... she'd er we lay sixty ton of top soil between us.

970 PB: Gosh!

Continuing past interaction style

'seeking' advice

labourer's relations

971 Partic. 2: You know that sort of thing. So it it was, it was always a part
972 and parcel of our life having a nice garden sort of thing but I was
973 the gardener and she was the labourer if you like. And, and so
974 I, when I was thinking about getting this garden done for ages I
975 talked to her because I couldn't make my mind up what I wanted
976 and eventually I decided what I wanted and think to myself
977 would she approve. I don't know whether she would or not.

Partnership
working
together

978 PB: So you talked to her about that?

979 Partic. 2: Mm

980 PB: Yeah, yeah

981 Partic. 2: Well, and and when I read the newspaper sometimes, I'm
982 reading the newspaper and I'll say, I'll say 'you know we were
983 watching the news I've just read', that sort of thing and still do
984 that. Not so much now probably as I did when it first happened
985 because I got a slight response you know but er I don't get no
986 response at all now. So I would say that that helps.. and you
987 know the carers were were wondering about what's wrong or if
988 something's wrong and the fact that I'm trying to get this
989 protocol where a doctor comes and visits her every so often. I
990 preach that I talk to my friends on the internet tell them to go
991 forward and see if they can do something about that.

Even though
she is unable
to respond

still
continues
past behaviour
interactions

fighting to
meet her
needs
campaigning?
rights?

continuing
interactions
knowing
he won't
get a
response

992 PB: Mm mm

993 Partic. 2: But in that case it's only the people who are unable to
 994 communicate that really want it. So people who can go to their
 995 doctors no problem.

996 PB: Yes

997 Partic. 2: Even though they don't know what's the matter is with them they
 998 can go to the doctors whereas [name of wife] can't, and er

999 PB: So taking care of her needs is something that helps you feel
 1000 close?

1001 Partic. 2: It feels that I'm doing something for her.

1002 PB: Mmm

1003 Partic. 2: You know, because the er you you feel now you've got to take
 1004 on the dual role erm looking after her and also I don't know I've
 1005 taken over the role of two in a way. You know I'm doing both
 1006 sides and it's something you, you have to do I think you can't, if
 1007 you can't carry on, I can't carry, I couldn't possibly carry on
 1008 being just me and leaving [name of wife] aside so I've had to try
 1009 try....

1010 PB: To absorb that?

1011 Partic. 2: Yeah. So all all that helps I suppose

1012 PB: And what about activities or behaviours or activities that that
 1013 make you feel less close?

1014 Partic. 2: Well going on my holidays was one big test because I didn't
 1015 know I could cope with going on my own so that that that's really
 1016 the biggest thing that happened that that made me realise that

*recognising
and depending
to needs*

? satisfaction

*Feeling
sense of
satisfaction
achievement
after
needs*

*taken over
2 roles
perceived
abandonment
of wife
if he
hadn't*

*in concern
not to
come -
fear of
abandoning
we on*

1017 [name of wife] is no longer part, my life in that sense. Because I
 1018 say we always we never went anywhere on our own on holiday
 1019 or anything like that, so that's I think that has been the biggest, it
 1020 was the biggest decision I made.

1021 PB: Mm

1022 Partic. 2: I didn't want to go anywhere we'd been together because I think
 1023 the memory would have been too poignant. I.. I just didn't
 1024 think I could cope with it. I went to my son's for the first time
 1025 when I went on holiday and er that was still the family thing.

1026 PB: Yes

1027 Partic. 2: But first thing, last year this year when I went on my own it was
 1028 a complete break and er I worried about that more before I went
 1029 but once I got there the people who I was with were very friendly
 1030 it softened it a little bit, it wasn't so bad and er I felt a bit guilty
 1031 actually about going so it, a ..a bit of a betrayal.

1032 PB: Mm

1033 Partic. 2: I think

1034 PB: Can you tell me more about that?

1035 Partic. 2: Well that fact that I was going away and enjoying myself and
 1036 leaving [name of wife] at home, and...and I knew full well she
 1037 would be looked after and er I made sure of all that but I still felt,
 1038 I, did I really ought to be going you know, was it was it the right
 1039 thing to do? I say it took me ages to make up my mind to go
 1040 and.... and when I got there I I enjoyed it and ..and even...

having to do things independently

wife longer in on her own

Sadness / loss

Sadness / loss

felt guilty / betrayal

guilt

guilt

guilt