

**A qualitative study of the way in which male carers of spouses with a working age dementia experience and perceive their role.**

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## Thesis Abstract

**Purpose:** The number of people with dementia in the UK is known to be increasing. A minority of this group will develop a working age dementia where onset will be prior to 65 years of age. It is suggested that many people with a dementia will be cared for on an informal basis by family or friends. This informal caring role has been shown to be psychologically and physically harmful. If people are to continue to offer the current level of input it is essential that their needs are understood and that they receive the appropriate support from services.

**Method:** A systematic literature search was carried out to determine what was known about caring for those with a dementia. Whilst there was some reference to gender differences in terms of coping styles little of the research had looked at how male carers needs might differ from female carers. To address this gap in the knowledge base a qualitative study was carried out using interpretive phenomenological analysis. The aim of the study was to explore how seven men whose wives developed a working age dementia experienced and perceived their caring role.

**Results:** Five themes emerged from the data: facing up to dementia, challenges to male gender stereotypes, issues of control, using psychological defences and loss. The most significant of these in terms of coping seemed to be perceived control. Whilst the one which appeared to have the most direct impact on the participants was that of loss and the grief process that this brought about. Many of the research findings mapped onto the model of caregiver stress developed by Pearlin *et al.* (1990)

**Conclusion:** This study helped to expand the current level of understanding about the specific needs of male carers whose wives developed a working age dementia. Furthermore, it highlighted the importance of perceived control over the way in which these men experienced their carer role.

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This study would not have been possible without the men who agreed to share their stories with me: I thank them all for being so generous.

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Finally I should acknowledge my boys; Stan, Dennis and George. Thankfully they remained oblivious to the whole process as only teenage sons can.

In memory of my dad.

### **Word Counts**

	Without references	With references
Thesis abstract	316	316
Literature review	7,944	9,585
Research Report	12,055	12,746
Critical Appraisal	3,467	3,611
Total	23,782	26,258

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### **Section 1.0: The Literature Review:**

Caring for a relative with a dementia and the specific issues relating to working age dementia.

Word count: 7,944

## Literature Review Abstract

**Purpose:** To examine the literature relating to caring for a close relative who develops a dementia. To explore the specific issues relating to working age dementia.

**Method:** Five electronic databases were scrutinised in a systematic literature search.

This was to look for literature focusing on the experience of male carers or the literature relating to the specific issues associated with working age dementia.

**Results:** The literature suggested that providing informal care for someone with a dementia was psychologically and physically harmful. In addition, differences were identified in the way men and women coped with caring for someone with a dementia and the amount of burden they reported.

From the existing literature, it is unclear what service provision is required to meet the needs of individuals caring for a partner who has developed a working age dementia. Furthermore, there is little understanding of the individual needs of the people who care for this group.

**Conclusions:** This review highlights the fact that male carers report lower levels of perceived burden than female carers. However, the literature is limited in the exploration of the way in which men experience this caring role and the lower level of perceived burden is generally explained in terms of coping styles. In relation to working age dementia there is little research looking at the specific difficulties that apply to this area.

Male carers whose spouses develop a working age dementia are a group overlooked by the existing literature base. Further research would help to develop a greater understanding of the difficulties faced by this group of people, their needs and the type of service provision required.

Key words: dementia care, spousal carer, male caregiver, pre-senile, early onset dementia.

Target Journal: Dementia: The International Journal of Social Research and Practice

## **1.1 Introduction**

### **1.1.1 Background Information Relating to Types of and Incidence of Dementia.**

Dementia has been defined as any neurodegenerative condition that is irreversible and which will, usually, result in memory and functional impairments (Lezak *et al.*, 2004). Whilst this is true it should be noted that dementia is not an homogenous entity and there are many different sub-types of the condition, caused by a variety of disease processes (McLennan, 1999). These can include Alzheimer's disease (AD), vascular dementia, fronto-temporal-lobe dementia (FTLD) (which includes Pick's disease), Huntington's disease, dementia with Lewy Bodies, Creutzfeldt - Jakob disease and alcohol related conditions, amongst others (Martin, 2006).

Within the general population of the UK the overall incidence of dementia is rising, with the latest report from the Alzheimer's Society (2007) estimating that it now affects around 683,597 people. Within the general statistics AD is the most prevalent, followed by vascular dementia. The evidence shows that the rate of incidence increases with age, and it is estimated that one in 50 people between the ages of 65-70 are affected, rising to one in five for those over the age of 80 (Alzheimer's Society, 2007). Given that the UK population is now living longer than ever before (Office for National Statistics, 2007), it is probable that this is a major reason for the overall increase. In addition, it is known that women generally live longer than men (Office for National Statistics, 2007) and are approximately twice as likely to be affected.

The UK Government has stated that the cost of dementia is around £14.3 billion per year; more than cancer, stroke and heart disease combined (Committee of Public Accounts [CPA], 2008). Furthermore, they estimated that over a third of care

needs are met on an informal basis (i.e. by family or friends), saving health services around £5 billion per year (CPA, 2008). Despite all of this it has been acknowledged that dementia has not been afforded the same high profile and resources as health issues such as obesity and coronary heart disease, and there is now increasing pressure from the Government to try and readdress this shortfall in service provision (CPA, 2008). With regard to the continued aging of the population and the increasing prevalence of dementia, it is estimated that by 2051 the total number of people in the UK with a dementia will be in the region of 1,735,087 (a rise from the current number of 154%) (Alzheimer's Society, 2007), which will of course result in further cost to the taxpayer. These statistics highlight why dementia is now high on the agenda for the Government, health services, researchers and, increasingly, the general population.

### **1.1.2 Background Information Relating to Working Age Dementia**

Dementia is often thought of as a condition that affects people in older age, and the figures given above, with regard to the increase in incidence related to aging, support this assertion. However, it is also recognised that younger people can develop the same range of conditions (McLennan, 1999). The National Institute for Health and Clinical Excellence (NICE) guidelines for dementia care (2006) acknowledge this and section 1.1.2.1 states that “Younger people with dementia have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care.”

Within the published literature this type of dementia is variously referred to as pre-senile, early onset, young onset or working age dementia and usually refers to people under the age of 65. For the purpose of this paper the term working age

dementia (WAD) will be used. The current figure for the incidence of WAD in the UK is estimated as 15,034, or 2.2% of the general population, with slightly more males affected than females (Alzheimer's Society, 2007). It should be noted that this overall figure has the caveat that it is based on referrals to services, and the report suggests that the real number may be up to three times higher. If, as suggested, the overall increase in the incidence of dementia is mainly due to the aging of the population, it might be expected that the incidence within the working age population would remain fairly stable over time and no future estimate of increased numbers is given in the Alzheimer's Society report (2007). In addition to this, the report suggests that FTLD, rather than AD or vascular dementia, is the most common cause of dementia in working age men (Alzheimer's Society, 2007). It does not, however, speculate on the most common type of dementia for working age women. This is contrary to an earlier estimate of the incidence of different dementias in a working age population when Newens *et al.* (1993) reported that AD accounted for around 47% of their sample, vascular dementia for around 16% and other dementias the remaining 37%.

### **1.1.3 Background Information Related to Male Carers**

It has been suggested that the majority of people who develop a dementia, regardless of age or sex, will, for at least some period of time, be cared for by a spouse or other close relative (Kramer, 1997). Research findings have shown that this can often have a detrimental effect on both the physical health and psychological wellbeing of these carers (Waite *et al.*, 2004). The literature regarding spousal carers has most often focused on females rather than males (Kramer, 2000); with the assumption being that females are far more likely to take on the informal caring role

than males (Kaye & Applegate, 1990). Stone *et al.* (1987), however, placed the figure of male spousal carers at around 36% in a US study and, more recently, Brown *et al.* (2007) suggested that this had increased to around 41% of spousal carers, showing that the discrepancy between the number of male spousal carers and female spousal carers might not be so great after all.

## **1.2 Reason for the Literature Search and Preliminary Research Question**

As dementia rates continue to increase it is, perhaps, more important to understand the needs of those who care, in order to be able to offer appropriate support and services. Brown *et al.* (2007) stated that “The experience of husbands caring for wives with dementia is an emerging area of study.” (p.353) and Beattie *et al.* (2005) suggested that this group appears to be both under researched and under resourced at present. Given the large number of published studies found by a search for generic dementia carer literature<sup>1</sup> this highlighted a gap in the knowledge base. It is also suggested that care provision varies across the UK and that people with WAD often fall between services. This is because the expertise in dementia lies mainly in Older Adult services whilst younger people are more likely to be directed towards Adult Mental Health services, often due to service capacity and funding issues (Allen & Baldwin, 1995). Therefore, research which highlights the specific needs of this group might help to inform future provision of services by identifying what carers see as the main issues, what support is required and which services might most effectively deliver this support.

In summary, the evidence suggested that the incidence of dementia in the general population is increasing. The majority of people with dementia are, at least for

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<sup>1</sup> In a basic enquiry of one search engine, using the term “dementia AND carer”, 830 articles were returned.

some time, cared for by a spouse or other family member. There is a large body of research looking at caring for a relative with dementia, but this mainly focuses on female carers of older people, and there appears to be little research into the experience of male spousal carers of people with WAD.

### **1.3 Systematic Literature Review**

#### **1.3.1 Method**

A systematic literature review was carried out using the following electronic databases: SCOPUS (All years to December 2007), Medline (1950 to December 2007), Ovid MEDLINE (1950 to December 2007), EMBASE (1980 to December 2007) PsychINFO and PsychARTICLES combined (all years to December 2007). Titles and abstracts were searched using a variety of search terms, and combinations of search terms. These terms included “dementia carers”, “male carers”, “spousal carers”, “early onset dementia”, “working age dementia”, “younger people AND dementia” and “pre-senile dementia”. In addition to this, references from these articles which appeared particularly relevant were also sought. Many of the searches generated duplicate articles, or articles which were unrelated to the study, and these were discounted from the review.



## **1.4 Findings of the Literature Search**

### **1.4.1 Literature Relating to Carers**

It has been suggested that the burden of care for people with dementia falls, in many cases, on the spouse or immediate family of the person<sup>2</sup> (Kramer, 1997). In an observational study of the care giving role Jansson *et al.* (2001) highlighted the complexity of being a spousal carer. They suggested that spouses provided not just physical but also emotional support for their partners in a wide range of ways, and they identified four major themes that were included: activities of daily living (e.g. personal care, food and administering medication); communication; supervision/surveillance and activity/stimulation. In summarising their findings they stated that spousal carers had "...undergone a transition from equal partner to caregiver and given up most of their lives to take care of their significant other." (p.809). In addition they suggested that caregivers often became extremely adept at meeting the needs of their partners and developed expertise in the role, despite the complexity and, on occasion, lack of support. However, despite the apparent development of new skills or expertise, taking on this role has repeatedly been shown to be detrimental to the carers' own physical and mental well-being (e.g. Kiecolt-Glaser *et al.*, 1991; Wright *et al.*, 1999; Pinquart & Sorensen, 2003).

### **1.4.2 Carer Burden and Health**

The detrimental effect on the carers own wellbeing has been widely researched. With regard to adverse health effects, Katon *et al.*'s (1982) study suggested that carers of people with dementia were 50% more likely to visit their GPs and 86% more likely to use prescribed medication than non-carers. Papastavrou *et al.*

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<sup>2</sup> Therefore, in context of this paper the terms carer or care-giver will refer to a familial carer rather than someone employed to provide care.

(2007) suggested that the negative consequences of taking on the carer role included emotional, physical and financial stress, and affected the carer's social, occupational and personal roles. This phenomenon has been termed 'caregiver burden' and is well evidenced in the literature (e.g. Davis & Tremont, 2007; Kaiser & Panegyres, 2006). Ballard *et al.* (1995) stated that whilst it was widely acknowledged that carers suffered stress and depression as a result of their role, the level of this was generally underestimated. They reported that there was an association between increased severity of the symptoms of dementia and carer depression. In addition, they found that increasing age (of the carer) and the quality of premorbid marital relationships were also major factors associated with the level of carer depression. They did not find any reduction of carer stress where the person with the dementia received day services or respite care. They concluded by suggesting that the role of being a carer in its own right was so stressful "that additional stresses [outside of the caring role] are of relatively little importance" (p. 62). However, there is evidence to suggest that older adults suffer higher levels of stress and depression than the general population, regardless of whether they take on caring roles or not (Laidlaw, 2004) and this might, to some degree, confound Ballard *et al.*'s findings. It is also possible that the types of day services available were not well suited to the carers' needs, and if this was the case it could offer some explanation as to why their stress levels were not reduced.

Similarly, Donaldson *et al.*, (1998) found that what they termed non-cognitive features of dementia, such as disrupted sleep pattern or psychotic phenomena (including auditory and visual hallucinations), were related to significantly higher incidence of stress and psychological morbidity in carers over a non-carer group. This in turn resulted in an increase in the perceived level of caregiver burden. In addition, they reported that being a female carer was a risk factor associated with psychological

morbidity, whilst, perhaps paradoxically, being a spousal carer (regardless of sex) was a protective factor against burden and distress. They found that, where services offered input and practical help around issues such as sleep disturbance, this resulted in a reduction of carer stress. This seemed to somewhat contradict the findings of Ballard *et al.* (1995) and it might suggest that, whilst there are certainly identifiable factors that influence the perception of the carer role, it is sometimes the complex interaction between these that resulted in higher levels of burden. This in turn might highlight why services are most useful when they meet the individual needs of the clients and carers.

In their paper Papastavrou *et al.* (2007) reported that just over 68% of their sample of familial carers were ‘highly burdened’ and that around 65% exhibited depressive symptoms. However, they also suggested that there were factors which mitigated the ‘amount’ of burden experienced. These factors included patient psychopathology (i.e. more severe and higher frequency symptoms and/or difficult behaviours might increase the amount of perceived burden), caregiver sex (again they found that females were more likely to experience greater levels of burden as opposed to males), household income (those with higher incomes reported lower levels of burden) and level of education (with those better educated reporting lower levels of burden). Further to this they reported a positive correlation between total caregiver burden and total frequency of problem behaviours. The behaviour they found most strongly correlated to increased burden was aggression. However, they did not state whether there was any difference between male and female carers with regard to this and it is possible that one group might be more affected by aggression than the other. In relation to the sex of the caregiver, they again found that women had higher levels of reported burden than men on the indices used. With regard to this, they reported

that women were more likely to adopt emotional coping strategies, whilst men used problem-solving strategies and were more likely to seek out social support, and they postulated that this could explain the higher levels of burden shown by women. It should also be noted that this study was carried out in Cyprus, and the authors themselves pointed out that within this cultural context women were expected to take on caring roles regardless of whether they wanted to or not. It may, therefore, be possible that contrary to the expected societal norms the male carers included in this study were more disposed towards the caring role, thus making it seem less burdensome for them. The authors also noted that the study assessed patients at different stages of the condition and it is possible then that the carer would report differing levels of burden depending on the progression of the dementia.

Perhaps most worryingly, in terms of carer health, were the findings of Schulz and Beach (1999). They reported that spousal carer strain could result in higher levels of mortality. They looked at a sample of 392 spousal caregivers against an age matched control of 427 non-caregivers. They found that after adjusting for socio-demographic and other health factors the mortality rate in the carers who were showing higher levels of strain was 63% above that of carers not experiencing carer strain and non-carers. They postulated about a number of possible contributory factors, such as higher levels of depression and/or anxiety, less chance to rest and limited opportunities to pursue other interests or activities (e.g. exercise).

Other factors have also been found to affect appraisal of the familial care giver role. These included the length of time spent caring and the relationship between the carer and the care-recipient. Okamoto *et al.* (2007) found that spousal carers were less likely to want to place their partner in residential care than other family members, such as adult children, who took on the caring role. This might mean that it is likely

that spouses will spend more time caring for their partners, and it has been suggested that this can lead to greater levels of perceived burden (e.g. Kiecolt-Glaser *et al.*, 1991; Argimon *et al.*, 2004). Kramer (2000) referred to this as the wear-and-tear hypothesis, whereby there is a gradual increase in perceived level of burden against the amount of time spent caring. However, her study (Kramer, 2000) suggested otherwise. Similarly to Jansson *et al.*'s (2001) findings Kramer reported that over time husbands adapted to the care-giver role, and levels of stress and depression actually reduced. McConaghy *et al.* (2005) also supported this idea. They suggested that those carers who used a more practical style of coping reported better well-being. However, they found that contrary to some other studies, there was no difference in this between male and female carers. In addition, they suggested that carers might under report their difficulties in order to "...play down their feelings of despair" (p.88), and that this could skew any findings. The main limitation to these findings is the relatively small sample size used (n=42), and within this group there were a disproportionate number of females (n=32) to males (n=10). The authors pointed out that this meant they were unable to use more sophisticated methods of analysis that might have resulted in more telling results.

Marital satisfaction and sexual intimacy have not featured in the studies presented so far. However, Simonelli *et al.* (2007) suggested that this can have a major influence on carer health and perceived burden. They compared a group of spousal carers whose partners had developed AD against a control group. Affective relationship and sexual variables were assessed using semi-structured interviews, whilst psychometric measures were employed to gauge the level of burden. They found that, although there was no difference in the reported level of affection shown between the carer group and control group, affective relationships were perceived to

be worse and the frequency of sexual intimacy was adversely affected in the carer group. This, they suggested, could lead to higher levels of perceived burden and depression. They also highlighted that few healthcare professionals had warned carers about the possible effect on marital relationships. They suggested that it was the role of professionals to foster an open atmosphere with regard to sexual issues so that carers might feel able to discuss this aspect of their relationships.

As can be seen many of the reported findings are consistent across the literature. It should be noted though that much of the research examined has employed quantitative methodology for examining this area. This can limit the scope of subjects to express what is important to them and focus only on what is being asked in the research question. Therefore Samuelsson *et al.* (2001) adopted a qualitative approach to try and illicit the factors that were important to carers of people living with a dementia. They interviewed eight familial caregivers of relatives with dementia. The sample was purposefully selected and consisted of two husbands, two sons, three daughters and one daughter-in-law. They used structural analysis to analyse the transcripts of the interviews conducted. Out of this analysis they identified six categories, which they postulated were interrelated. These were: symptoms of dementia; patient's situation; caregiver's emotions; previous relationship; caregiver strain and caregiver's coping strategies. As can be seen these closely match the categories examined in the other studies. This might then appear to lend credence to the corpus of research, and to validate some of the questions being asked.

Robinson-Wheelan *et al.* (2001) looked at whether these higher levels of burden continued even after people ceased to carry out this role. In a four year study a group of former spousal carers was compared against current carers and non-carers. They found that the former spousal carers actually experienced decreases in perceived

stress and negative affect to such a degree that by the end of the study they mirrored the non-carer group. However, other areas, such as positive affect and loneliness, remained at around the same level as the current carer group. The authors specifically remarked on the levels of depression in the former carer group, which remained around the same as the carer group and significantly higher than the non-carer group. They concluded that whilst the former carer group did not get worse they did not, on the whole, get much better. They also warned of the long-term health impact this could have on this group, predicting more strokes and higher levels of functional impairment in this group. It is possible that this might be connected to several factors such as a lack of control over the care being provided or even a sense of guilt, or failure, at no longer being able to provide for a spouse.

Graham *et al.* (1997b) looked at what impact a carer's knowledge of the dementia process had on their perception of the role. They found that those carers who were better informed reported lower levels of depression. However, they also found that this same group experienced higher levels of anxiety, which, they suggested, was contrary to expectations. They put forward two theories to explain this: firstly, they suggested that carers who sought out information were more likely to be aware of the expected progression of the dementia, and, therefore, the associated difficulties that went with this, as well as anticipating the loss that this would result in; and secondly, they suggested that it could be down to anxious carers being more likely to seek information in the first place. This was echoed by Mcfarland and Sanders (1999) who found that males caring for someone living with a dementia actively sought out information as a way of taking control of the dementia process. This phenomenon appeared similar to information seeking behaviour in health psychology. For example, Miller *et al.* (1988) looked at how high and low-monitoring

behaviour (that is how much or how little information people sought out in regard to their own health) affected their perceived level of well-being and suggested that acquiring knowledge of medical processes helped certain types people to cope.

In a separate paper (Graham *et al.*, 1997a) looked at how carers received information from services. They reported that those carers with less knowledge relating to dementia reported feeling less able to cope, and, therefore, had higher levels of burden, whilst those with more knowledge had a better understanding of the process and felt more able to cope. However, they highlighted inconsistencies in the level of information provided by professionals involved in the dementia services, and suggested that this needed to be improved. It should be noted that in their discussion Graham *et al.* pointed out the difficulty of obtaining a balanced sample in this kind of research. In their study they found that there was an over representation of carers in contact with secondary services, and possibly therefore receiving higher levels of support, which might have biased their findings. It is possible that in choosing to seek out knowledge regarding the dementia process some carers are trying to regain control of a situation that appears chaotic and beyond their control. Whilst this knowledge may ultimately result in greater levels of anxiety it might also offer a sense of predictability regarding the process.

It appears that there is a general consensus in the research literature that there are negative effects of being a carer. In addition it has been identified that there are mitigating factors which influenced perceived levels of carer burden (e.g. women were more likely to report higher levels of burden; severity of symptoms increased level of burden; and being a spousal carer reduced level of burden). However, Kramer (1997) reported in her study of strain and gain in male spousal carers that there might be positive aspects of taking on the carer role which result, not only in reduced levels



of burden, but in what is termed carer 'gain'. This gain included husbands feeling a sense of pride in their role as carer, or of them feeling closer to their wives as a result of taking on the role. The findings suggested that not only did factors such as the carer's level of education and a problem-focused coping style help to guard against a negative perception of the role and reduce burden, but in some cases they actually led to a more positive appraisal of the role. Interestingly in this study, with regard to level of education it was found that there was an association between having a lower level of education and appraisal of gain, which appears contrary to other studies (e.g. Donaldson *et al.*, 1998; Papastavrou *et al.*, 2007). As a possible explanation for this, Kramer suggested that it could be due to better educated husbands having previously held higher professional/social status and, therefore, being more aware of the differential between their previous position and their caregiving role. Conversely it could be that for the lower educated the new, important role of carer made them feel more valued/worthy/proud of their role in some way. Perhaps, though, this anomaly is partly explained by the research paradigm itself, with Kramer's study looking for, and finding examples of carer gain, whilst the other studies were more focused on measuring level of strain (or burden).

With regard to family caregiving for those who had developed a dementia, Zarit and Edwards (2008) stated that the "Perhaps the most critical point... is that people adapt quite differently to similar situations" (p.260). In order to explain why this might be they discussed the model of caregiver stress developed by Pearlin *et al.* (1990). This model set out a dynamic process that included Primary Stressors, Secondary Stressors, Outcomes (i.e. health and well-being) and the impact that Social Context and Resources had on these. In the model the primary stressors were seen as those actions directly related to the needs of the person with the dementia and the care

and assistance provided. The secondary stressors were those difficulties that resulted for a person when they took on a caring role. This included the negative impact on other relationships as well as disruption of work and social contact. Also included as a secondary stressor is what was termed intrapsychic strain. This suggested that some caregivers could become so immersed in their role that they lost their own sense of identity.

The model also allowed for both the primary stressors, secondary stressors and outcomes to be affected by resources and social context. Resources could be psychological (such as level of self-esteem or coping style), social (including access to emotional support) or economic (in terms of their financial situation) and how carers perceived their role would be affected by these factors. For example, a carer with a high self-esteem, close family support and adequate finances would be likely to report lower levels of strain than one with poor coping strategies, who had limited social networks and was living on a low income. This might go some way to explaining why in certain cases those who are faced with what might appear to be very demanding caring roles report lower levels of strain than others who seem to have fewer demands placed upon them.

Social context included factors such as closeness of relationship, with it being suggested that spouses or daughters, who were seen as being closest to the care recipient, were more likely to offer the greatest amount of assistance for the longest period. It also included cultural differences and socioeconomic status. It was suggested that different expectations existed within different cultural or ethnic groups, and that certain groups were seen to report lower levels of burden or stress than others in similar circumstances. In terms of the effect of socioeconomic status Zarit and

Edwards (2008) suggested that in America at least this was not as simple as it might appear. Whilst it might be expected that those of lower economic status would have fewer economic resources, resulting in them taking on more of the care burden, they tended to have more access to public support networks than those of from more middle-class backgrounds. In addition, it is suggested that those from lower socioeconomic backgrounds might have more access to help from extended family and friendship networks

### **1.4.3 Gender differences in carer coping**

The gender difference in caring was highlighted by Kaye and Applegate (1990), who explored which family members were most likely to take on caring roles. They found that traditionally caregivers had been female relatives, including wives and daughters. They suggested that this was reflected in the existing literature with an implicit assumption that when talking about familial carers they were in fact referring to female relatives. As a possible explanation for why women most often took on this role they stated that "...some of the gender role differences in caregiving can be explained by traditional Western sex-role socialization" (p.290) suggesting that females were implicitly prepared for taking on caring roles, firstly by parents and then by teachers, whereas males were not. However, they postulated that due to external factors, such as financial pressure and occupational priorities, this would be unlikely to continue to be the case, and that women were increasingly more likely to need to work. Therefore, it would be more likely that the caregiver role would need to be shared by males and females. In conclusion they suggested that, in light of previous research being focused primarily on female carers, more research focusing on male carers, their needs and their coping strategies was required.

Since the Kaye and Applegate (1990) study there has been more research focused on male carers and/or gender differences within the caring role (e.g. DeVries *et al.* 1997; Garity, 1999; Hooker *et al.* 2000), although this is still somewhat limited when compared to the generic carer literature. However, within this body of research several key findings have been consistently identified: firstly, that female carers were more likely to suffer distress due to taking on the caring role; secondly, that female carers are more likely to access services than male carers; and thirdly, that women tended to adopt what is termed emotionally-focused or avoidant coping styles, whilst men used problem-focused or instrumental coping styles.

In a Japanese study of gender differences for WAD carers, Takano and Arai (2005) reported that their findings mirrored those of Western studies, in that women there also reported higher levels of burden. This level of strain differed according to age, with younger women reporting higher levels of strain. They hypothesised that this could be explained by the loss of family income, and point to factors such as dependent children adding to this strain. They state that when the male develops a WAD “the family often lose the majority of their income for living” (p.75). Whilst this might be true, it is possibly culturally specific to a more traditional view of the male being the ‘breadwinner’ and perhaps fails to take account of factors such as the female being expected to give up work to take on the caring role. Freyne *et al.* (1999) carried out a comparative study of those caring for a person with WAD and carers of those with later onset dementia. They found that the carers of those with a WAD exhibited significantly more burden than the other group and they suggested reasons why this might be so: firstly, the negative impact on factors such as social, financial and occupational situation was more accentuated in the younger group; secondly that there was a greater negative impact on family life (i.e. through suffering financial

hardship due to at least one party not being able to work and that there might be dependent children within the family) and thirdly that there was a lack of designated services for this group of people. With regard to the final point it should be noted that this study took place in the Republic of Ireland. However, Beattie et al. (2005) found that this lack of specialist service for those with a WAD was equally applicable to the UK.

#### **1.4.4 Incidence and aetiology of WAD**

As stated earlier the Alzheimer's Society (2007) estimated the incidence of WAD in the UK as 15,034. However, this figure had the caveat that the true number may be up to three times higher, due to under-presentation to services or under-reporting by professionals. Harvey *et al.* (2003) tried to account for this under-reporting by conducting a wide ranging survey of GPs, psychiatrists, psychologists, neurologists, geriatricians, general physicians, social service departments and hospitals in four London Boroughs. They identified a total of 185 cases that met their diagnostic criteria for WAD. Based on this they extrapolated the total UK figure to be 18,319 (confidence intervals 15,296-21,758), or 54 per 100,000. They further broke this number down into causes of dementia and found that AD accounted for 34% of their WAD population (as opposed to 80% of the later onset dementia population), and that conditions such as dementia with Lewy Bodies and FTLN were more prevalent in the study group than the general population.

These figures relating to the most common causes of WAD were echoed by Panegyres *et al.* (2007) in a longitudinal American study. They followed a group of 226 WAD patients for a mean duration of 4.59 years ( $\pm 2.23$  years) to establish the cause and progression of the dementia. It was found that in this group FTLN (19%)

was more common even than AD (11.9%), and that memory loss was the most common presenting problem amongst the sample. One additional finding, which perhaps highlights the complexity of diagnosing a WAD, was that of the original cohort of 254 suspected dementia patients, around a quarter (24.3%) were actually found to have other types of psychiatric disorders. Panegyres *et al.* (2007) stated that the area of WAD was “...under-recognized, misunderstood, and inadequately managed with limited resources and services in most countries” (p.48). In conclusion they emphasised the need for a “...rigorous diagnostic workup including consideration of general medical conditions” (p.54) when assessing for dementia, and they suggested that this would be best achieved through the use of a multi-disciplinary approach.

#### **1.4.5 Progression of WAD**

It was noted that during the course of the Panegyres *et al.* (2007) study 15 of the cohort died. With regard to post-diagnosis survival time Barclay *et al.* (1985) stated that “...patients with presenile onset of [AD] have decreased relative duration of survival compared with senile onset” (p.91), and they suggested that dementia had a more malignant course when initially manifested at an earlier age. However, Kay *et al.* (2000) contradicted this finding. Their study looked at the long-term effects of WAD on a population in the northern England health region. They collated figures for the period 1985-1989 and recruited a sample of 233 working age patients who had a diagnosis of either vascular type dementia or AD. They then followed up this sample between 8-12 years later and found that 192 of the cohort had died during this period. Median survival post-diagnosis was 6.00 years for those with vascular dementia and 6.08 for those with AD which they suggested was in line with the overall mortality

rate in those over 65. Further to this, in a more recent study of an over 65 cohort, Xie *et al.* (2008) found that the median length of survival was actually less than that, at 4.1 years for women and 4.6 years for men.

As can be seen, the figures relating to length of survival are contradictory and Luscombe *et al.*, (1998) suggested that some of the discrepancy might be accounted for by the difficulty medical practitioners had in identifying dementia at an early age. In practice a GP might have around ten minutes to evaluate the symptoms presented by someone, who may be forgetful and confused, and differentiate them from more usual presentations such as depression or anxiety (e.g. Newans *et al.*, 1994; Ferran *et al.*, 1996). Even when this is achieved Williams *et al.* (2001) pointed out that the lack of specialist services available made it difficult for GPs to know where to refer people onto for further investigation and diagnosis. This was highlighted by Allen and Baldwin (1995) who found that GPs tended to refer to Older Adult services whereas hospital doctors referred to neurologists. They concluded that, whilst patients were more likely to receive better post-diagnosis interventions from Older Adult services, the correct diagnosis was better achieved by specialist Neurology departments. However, Doran (1997) suggested that diagnosis of WAD should be a clinical judgement based on a range of information, rather than relying on one strand of evidence. He suggested that to enable the clinician to build a thorough picture of the presenting problems, and to rule out any differential diagnosis, a multi-faceted approach should include clinical examination, neuropsychological assessment and structural imaging. Whilst it is likely that this is correct, it is a time consuming and costly process which relies on many professionals making the right choices at the right times, and this might go some way to explaining why the correct diagnosis can be missed or delayed.

#### **1.4.6 Appropriateness of Services for WAD**

As previously stated, Allen and Baldwin (1995) suggested that those with a WAD were better served by Older Adult services once diagnosis had been made. However, it has also been suggested that these services, whilst ‘acceptable’, are not ideal for those with this client group (Delany & Rosenvinge, 1995). They concluded their study by suggesting that specialist provision would better serve this group, but that due to the small numbers affected that it was “...unlikely to be feasible” (p.600) to provide such services. Beattie *et al.* (2005) supported the provision of specialist services. They suggested that there were three acceptable alternatives: firstly, to provide services in individuals’ own homes; secondly, for people to access “the few specialist services that exist, mainly in urban areas” (p.77); and thirdly, that service providers become more flexible in their ability to adapt services to meet individual and local needs. However, in an earlier review of the literature around the provision of services for people with WAD, Beattie *et al* (2005) suggested that whilst many of the papers argued that younger people with dementia, and their carers, had different needs from older people, they actually made “...unspoken ageist assumptions...about older people” (p.210). They further explained that whilst they did not necessarily disagree with this point of view, they felt the assumption was made without the scientific evidence to support it.



## **1.5. Discussion**

It is estimated that dementia care currently costs the UK tax payer around £14.3 billion pounds per year and that a further £5 billion is provided on an ‘informal’ basis by family and friends (CPA, 2008). Furthermore, the incidence of dementia is set to rise as the population continues to age and it is suggested that by 2051 the total number of people with dementia in the UK will exceed 1.7 million (Alzheimer’s Society, 2007). That is over a 150% higher than the current figure and this will bring with it an extra tax burden. Whilst these figures illustrate the financial burden of dementia care they do show the detrimental impact the condition has on all those who are touched by it.

### **1.5.1 Discussion of Carer Literature**

Perhaps the major theme to emerge from the carer literature was how much the role impacted adversely on the carers’ own physical and psychological wellbeing (e.g. Katon *et al.*, 1982). Certain factors were highlighted as adding to this perceived burden, such as the length of time spent caring (Kramer, 2000), the frequency of problem behaviours (Papastavrou *et al.*, 2007) and disrupted sleep patterns (Donaldson *et al.*, 1998). However, the research also identified factors which appeared to lessen the perceived levels of burden, such as appropriateness of input from services (Donaldson *et al.*, 1998) and the relationship between carer and care-recipient (Okamoto *et al.*, 2007). Sex of the carer was repeatedly identified as having an influence on how people managed the role, with male carers generally reporting lower levels of burden than female carers (DeVries *et al.* 1997; Garity, 1999; Hooker *et al.* 2000). However, Donaldson *et al.*’s (1998) findings somewhat confounded this

assertion by suggesting that being a spousal carer, regardless of sex, protected against perceived burden.

In Graham *et al.*'s (1997b) study knowledge of the dementia process was seen to have an effect on the perceived level of burden. They suggested that whilst providing appropriate information lowered carer depression levels it increased their anxiety levels. McFarland and Sanders (1999) found that information seeking was a specific coping style adopted by male carers, and that it gave them a sense of control over the condition. It should be noted though that even where there were factors that helped to mitigate how carers viewed their role they still reported higher levels of burden over similar non-carer groups, and that this generally continued even when the carer role ended (Robinson-Wheelan *et al.*, 2001).

Whilst the literature was generally good at identifying and describing the factors that influenced the way the caring role was perceived it did not, perhaps, explain why those factors were important and why some of the findings were anomalous or paradoxical. For example, with regard to the different levels of perceived burden a female carer was a risk factor resulting in higher levels of reported burden, whereas male carers were shown to report lower levels of burden (e.g. Garity, 1999; Takano & Arai, 2005). This was generally explained in terms of coping style, with it being suggested that men adopted more pragmatic, problem focused ways of coping, whilst women used more emotionally focused coping styles (e.g. Kramer, 1997). However, to fully understand this phenomenon it might have been helpful to further break it down and look at why a more pragmatic coping style lowered the perceived levels of burden. One possible explanation might be that by adopting a pragmatic/solution focused approach men were more likely to seek out social or professional support, and that this extra support actually reduced their perceived

burden rather than their coping style *per se*. Further to this, some of the literature suggested that women were traditionally and culturally expected to be able to care, whilst there was no such expectation of men (e.g. Kaye & Applegate, 1990; Papastavrou *et al.*, 2007). Therefore the extra levels of perceived burden women reported might have been as a result of the difficulties they had carrying out such complex care weighed against the expectation that they should be able to do so, rather than them being less able to cope than men.

Perhaps the best overall explanation of the differences found in these studies was that offered by Pearlin *et al.*'s (1990) dynamic model of caregiver stress as described by Zarit and Edwards (2008). This offered possible explanations as to why in certain circumstances some people reported lower levels of stress than those facing similar situations. It also took into account how mitigating factors, such as socioeconomic status and coping style, impacted on the way carers perceived their role without oversimplifying the situation. It also allows for the dynamic nature of caring for someone who has developed a dementia and the way in which the role changes over time.

### **1.5.2 Discussion of the WAD Literature**

Much of the WAD literature focused on service provision or the aetiology and progression of the condition. With regard to aetiology it was interesting to note that contrary to later onset dementia FTLN was more common than AD (Panegyres *et al.*, 2007). A possible explanation of this phenomenon is that FTLN levels are more stable throughout the lifespan, whilst AD is generally an artefact of aging (supported by the percentage increase as people grow older). This then would give the impression that FTLN is more common. The Alzheimer's Society (2007) estimated that WAD

affected around 2.2% of the UK population. However, Harvey *et al.* (2003) suggested that there was a general underestimation of the incidence and that the true figure was likely to be higher. Even so, this is still a relatively small number of people, and this might help to explain why there is an apparent lack of understanding of the condition and why specialist services are limited (Luscombe *et al.*, 1998).

Panegyres *et al.* (2007) reported that this lack of understanding is also present within the medical profession and they found that many people with WAD were misdiagnosed.. They also stated that specialist services were limited and inadequately managed. This was in line with the findings of Beattie *et al.* (2005) who warned about the lack of appropriate service provision in the UK. However, there did not seem to be any clear agreement regarding what form appropriate service might take. Allen and Baldwin (1995) suggested that people with WAD would be best served by Older Adult services. However, Delany and Rosenvinge (1995) and Beattie *et al.* (2005) suggested that more specialist services would be better at meeting the needs of this group.

### **1.6. Implications for Future Research**

It has been shown that the role of carer is extremely stressful and can have detrimental effects on both psychological and physical well being. Despite this it seems that little of the existing literature has tried to tease apart why some individuals or groups of people appear better able to cope with the burden of being a carer than others. In addition, the area of WAD is poorly provided for by services, poorly understood by professionals and public alike and poorly researched. It would be useful therefore to combine these two under researched areas and adopt a qualitative approach that allows for the exploration of individual experience. By doing this it

might help to develop our understanding of the challenges that male carers face, of the mechanisms that enable them to manage these challenges and of the type of help that they require from services to enable them to maintain their own psychological and physical well-being whilst they are carers.

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## **Section 2.0: The Research Report.**

A Qualitative Study of the Way in Which Male Carers of Spouses With a Working Age Dementia Experience and Perceive Their Role.

Word count: 12,055.



## Abstract

**Purpose:** Working age dementia affects around 2.2% of the UK population. Many of these people will be cared for by a family member or friend. This informal caring role has been shown to be psychologically and physically damaging. However, little is known of the way in which male carers whose spouses develop a working age dementia experience their role.

**Method:** A purposeful sample of seven male carers was recruited from within an NHS Trust with specialist working age dementia services. The participants were interviewed and the data was analysed using interpretative phenomenological analysis to examine how these individuals experienced and perceived their caring role.

**Results:** Five themes emerged from the data: facing up to dementia, challenges to male gender stereotypes, issues of control, using psychological defences and loss. These themes came out of the researcher's interpretation of the data and were grounded in the transcripts.

**Conclusion:** Perceived control was identified as a major factor in the way this group of men appraised their caring role. Participants described feeling left out of the process once professionals became involved. The emergent theme that had the most direct impact on the participants was that of loss. Many of the findings of the study mapped closely onto Pearlin *et al.*'s (1990) model of caregiver stress. Routine access to psychological therapies might be beneficial in some cases.

## 2.1 Introduction

### 2.1.1 Background Information

Dementia is a neurodegenerative condition that is irreversible and will lead to memory and functional impairment (Lezak *et al.*, 2004). A report by the Alzheimer's Society (2007) suggested that dementia affects between 650-700,000 people in the UK and that it costs the Government around £14.3 billion per year to provide services. A large percentage of care for those with a dementia is provided informally by family members or friends and the Committee of Public Accounts (2008) estimated that this saves a further £5 billion per year. The Alzheimer's Society (2007) report postulated that by 2051 the incidence of dementia will have increased by over 150%, adding to the care burden. Within these figures there is a minority of people who will develop a dementia before 65 years of age. This condition is referred to as early onset, pre-senile or working age dementia (WAD). The current prevalence rate for WAD is estimated at 2.2% of the population (Alzheimer's Society, 2007), although the report warns that the actual figure could be up to three times higher.

Research has consistently shown that caring for someone with a dementia can be physically and psychologically harmful (e.g. Katon *et al.*, 1982; Papastavrou *et al.*, 2007) and these ill-effects are shown to continue even after the person no longer fulfils the carer role (Robinson-Wheelan *et al.*, 2001). In fact it has been suggested that caring for someone with a dementia can be so damaging that it can lead to increased mortality rates for carers (Schulz & Beach, 1999). Other studies have shown that while all carers reported higher levels of burden than non-carer groups (Miller *et al.*, 1988; Donaldson *et al.*, 1998) there were factors that mitigated the level of perceived burden. These factors included; sex of the carer (McConaghy *et al.*, 2005),

length of time spent caring (Kramer, 2000) and the type and difficulty of behaviours displayed by the person with dementia (Papastavrou *et al.*, 2007).

The figures relating to the increasing incidence of dementia perhaps illustrate why it has now become an important issue for the Government, the general public and those services providing dementia care. Furthermore, the research evidence showing how damaging caring for someone with a dementia can be highlights why it is important to understand the difficulties of the role and to offer appropriate support to carers.

### **2.1.2 Research Question**

The carer literature has shown that some carers report lower levels of burden than others. However, little of the existing corpus of research has focused on the individual experience of carers in a way that might help to tease apart what makes this difference and to explore why, in general, men report being less burdened by the role than women. In addition, there are few studies that look at the experience of carers whose spouses' develop a WAD, although it has been suggested that this is an area worthy of further investigation (Beattie *et al.*, 2005). With this in mind the current study employed a qualitative methodology to explore the individual experience and perception of male carers whose spouses developed a WAD.

The key questions addressed by the study were:

- How did men perceive and experience their caring role?
- How did they feel their role within the relationship had changed?
- What did they find difficult within the role?
- What helped them cope with the role?

## **2.2 Methodology**

### **2.2.1 The Research Design**

It has been suggested that a qualitative approach can enable the researcher to examine people's individual experiences in greater depth than through the use of quantitative methodology (Barker *et al.*, 2002). Samuelsson *et al.* (2001) postulated that it was useful to employ a qualitative approach to fully explore the individual experience of those caring for a family member with dementia. Interpretive Phenomenological Analysis (IPA; Smith, 1996) is seen as particularly well suited to making sense of individual experiences of phenomena and processes (Brocki & Wearden, 2006).

The current exploratory study employed a qualitative approach, combining semi-structured interviews with IPA in order to examine the individual experiences of male carers whose spouses developed a WAD. This area is under researched and little is known of the experience and needs of this group (Beattie *et al.*, 2005). IPA was chosen in preference to other qualitative models, such as grounded theory, in order to allow for a full exploration of the role from the individual carer's perspective, rather than to try and build a model of the process.

### **2.2.2 Interpretive Phenomenological Analysis**

The researcher adopted the IPA approach described by Smith *et al.* (1999). This places the emphasis on exploring the phenomena as described by the participants. The interpretative element is concerned with the researcher's understanding of what the participants are saying. These interpretations will be

subjective and the methodology accepts that the researchers own preconceptions will influence the way in which he or she views the data. However, there is an overriding requirement to show how the interpretations are grounded in the data.

This methodology allowed the researcher to select a purposeful sample from a specific population. In this case the sample consisted of male carers whose spouses had developed a WAD. The aim of the study was to explore and interpret individual accounts presented by this group.

### **2.2.3 Researcher's Position**

The researcher had clinical experience of working with people caring for a person with a dementia. In addition he had cared for an elderly male relative. This resulted in the researcher having an interest in the male carer role. The researcher believed that carer's needs were not always considered when establishing services. He felt that offering appropriate support to carers would ultimately benefit the person with dementia by enabling a better standard of care, the maintenance of important relationships, stable environments and a reduction in psychological distress for all involved. In his own clinical practice the researcher utilised systemic, narrative and integrative ideas to inform his work.

In relation to the data collected the researcher held the belief that the participants constructed their account of events based on their interpretation of the experience and informed by their expectation of the research process. This would suggest that whilst the account given might differ depending on the circumstances in which it was given it remained true to the participant's belief in what they had experienced and it had validity at that time. It was also likely that the accounts were influenced by the demographic make up of the sample. The participants were all white

British males recruited from a relatively small geographical area and were in contact with specialist services. It was, therefore, probable that their experiences would differ to some extent from other groups of people.

## **2.3 Participants**

### **2.3.1 Recruitment of Participants**

A specialist Social Worker and two specialist services for WAD from within an NHS Trust were contacted and asked to invite male carers who fulfilled the study's criteria to participate. Potential participants were provided with a brief explanation of the study by a lead professional from within the specialist service. If they agreed to potentially participate their contact details were passed to the researcher who briefed them more fully on what this would involve.

### **2.3.2 Inclusion and Exclusion Criteria**

The inclusion criteria specified that participants should be male spouses or long term partners who had cared for a wife or female partner diagnosed with dementia prior to the age of 65. In addition, all participants had to speak English as a first language. This was to try and ensure equity of data. Potential participants were excluded if the wife or partner had a pre-existing condition which necessitated care.

Smith and Osborn (2003) suggested that a sample size of around six participants was sufficient for a project employing IPA. They stated that if the data collected were rich enough this would provide enough cases to allow for similarities and differences to be adequately explored, without overwhelming the researcher. For this study the researcher interviewed a total of seven participants.

### 2.3.3 Participant Information

A total of seven participants were recruited for the study. They were all white British males and ranged in age between 57-66 years at the time of interview. Table 1 (below) details relevant information relating to the participants and their spouses<sup>3</sup>. At the time of interview all the spouses were living at home, other than Tracey who had moved into residential care.

Table 1: Relevant Participant Information

Name of participant and spouse	Participants' age at the time of interview	Spouses' age at the time of interview	Diagnosis	Length of time since diagnosis	Participants' current occupation
1. Mark & Jane	59	61	FTLD	4 ½ years	Carer
2. Tony & Sue	58	60	AD	1 ½ years	Full time employment
3. John & Tracey	57	58	AD	6 years	Full time employment
4. Ken & Mary	61	59	FTLD	6 years	Retired
5. Roy & Paula	66	66	FTLD	11 years	Retired
6. Kevin & Erica	63	63	AD	1 ½ years	Full time employment
7. Ian & Paula	65	52	AD	1 ½ years	Retired

(Occupation was listed as given by participants)

## 2.4 Procedure

### 2.4.1 Ethical Considerations

It was suggested that asking people to recount their experience of caring for someone with a degenerative condition could cause psychological distress (Patel *et al.*, 2005). It was important, therefore, that potential participants were made aware of what would be expected should they take part. In addition, they were given access to

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<sup>3</sup> Please note that the names of participants and spouses have been changed to protect their anonymity. All other information is as given.

an appropriate person who could help should any difficulties arise as a result of participation. Each participant was provided with a Participant Information Sheet (Appendix 1) explaining the process. The lead researcher then contacted them to offer further explanation of the process and answer any questions. Participants were informed that they had the right to withdraw from the interview process or ask for the removal of any data collected at any stage of the study.

Although the participants were not derived from a clinical population within the NHS they were all recruited through specialist NHS services. Therefore, a positive ethical opinion was obtained from an appropriate NHS Local Research Ethics Committee (Appendix 2) and the University of Leicester Ethics Committee (Appendix 3).

#### **2.4.2 Interview Schedule**

An interview schedule (Appendix 4) was developed which was intended to gain insight into the experience of caring for a spouse with WAD. Due to the very small number of potential participants this schedule was not piloted in advance of the interviews. However, the researcher consulted with a male spousal carer, who did not meet the study's inclusion criteria, before developing the schedule to discuss possible topics. A draft schedule was scrutinised by a Clinical Psychologist with experience of the client group and a member of the academic staff at the University of Leicester who was familiar with using IPA methodology.

#### **2.4.3 The Interviews**

Appointments were arranged at a venue and time of the participants choosing. Participant Information Sheets were posted out prior to the interviews. Six of the participants were interviewed at their home addresses and the remaining participant



was interviewed at his work address. At the time of interview participants were presented with a consent form to sign (Appendix 5). The interviews were recorded on a digital recorder. The interviews lasted between 16 minutes and 66 minutes.

Following the interviews the researcher recorded initial impressions in his field diary.

An example of this is given below:

Figure 1: Extract from the researcher's reflective diary relating to the interview with Tony.

*dd.mm.2007*

*Tony seemed anxious to tell his story on his terms from the start. He had hand written two sides of A4 paper with notes that appeared to be in chronological order detailing everything that had happened. He read through these notes in an orderly fashion and referred back to them (? reflective of him being an accountant?). As the interview progressed he seemed to find it more and more difficult and at times he became quite angry about the way in which he felt let down by professionals.*

*It didn't seem that Tony was able to relate to his own emotions or feelings regarding his role- whenever I tried to bring it round to how he felt he seemed to end up talking about Sue, and how she was. I don't feel as though I controlled the interview as well as I wanted to.*

*I came out feeling drained and quite down. I think Tony's transference was difficult for me to deal with. Having already had the impression from our phone conversation that he was an angry man I wonder as well if my pre-conceptions/expectations played a part in the way I feel about it now?*

#### **2.4.4 Data Collection and Analysis**

Interviews were transcribed by a professional transcriber. Participants were aware of this and the transcriber signed a confidentiality agreement in advance of carrying out the work (Appendix F). The researcher then checked the transcripts against the recorded interviews for accuracy and removed identifying data such as participant/spouse/family names, names of clinicians, names of hospitals/clinics and services accessed (see Addendum for transcripts).

### 2.4.5 Line Coding and Thematic Coding

Each transcript was re-read several times for the purpose of analysing the data. Smith *et al.* (1999) suggested that this process of re-reading the transcripts was an important part of the procedure and allowed the researcher to become ‘intimate’ with the data. Following this the researcher added line by line coding into the right hand margin of the transcripts (Figure 2 below). This was to ensure that all the transcripts were given equal attention and that all potential areas of interest were highlighted. Whilst this process has been described in linear terms it should be noted that on each reading of the transcripts the researcher was formulating ideas about what was important, interpreting what had been said, developing emergent themes and thinking about the data in context of other interviews.

Following on from this the researcher reviewed the line by line coding and developed emerging themes based on his interpretation of the data. These were added into the left hand margin of the transcripts (Figure 2 below).

Figure 2: Extract from an interview showing line by line coding and emergent themes.

Emergent theme	Extract from Interview with Kevin: lines 17-29	Line by line code
17-24 confirmation  25 expert knowledge 26-29 age/unfairness	I did yeah. I went to see the doctor first erm we were on holiday in Scarborough and it was just little things and forgetfulness and missing losing things and I made an appointment to see her own doctor then and er went to see him and he says oh I'll send her to a specialist, I said all right and then we went there he says oh she had some tests and whatever then we went back again and er that's when he told me you know that er (.). But her mother went the same you see so I'd got an inkling what was what was happening anyway (.). cos her mother ended up in a care home in the end but her mother was older you see, Erica's only sixty- sixty odd and her mother was eighty in her eighties I think when she got it.	yes little things forgetfulness, losing Dr's appt specialist tests specialist diagnosed Inkling mum in care home mum older, 66 now mum 80s

### 2.4.6 Memo Writing

As the themes were developed the researcher made separate memo notes to enable him to bring to mind what processes had led to them. For example, in relation

to the above extract the memo regarding the emerging theme ‘confirmation’ read “*confirmation- just as I suspected, piecing together the clues- using prior knowledge to make sense of it all*”. This contemporaneous keeping of notes was an important part of the process and allowed for external validity checks by the research supervisor.

#### **2.4.7 Methodological Rigour**

With all qualitative approaches to research it is important that there are checks in place to ensure that the findings can be verified. Elliot *et al.* (1999) suggested a number of ways to ensure methodological rigour was adhered to when using qualitative research approaches. These included: owning one’s own perspective; situating the sample so that the reader might judge how relevant the findings might be to other areas; grounding in examples; and providing credibility checks to ensure methodological rigour.

To ensure the credibility of this study the researcher employed a number of strategies. A ‘field’ diary was kept throughout the research project to allow contemporaneous reflection on the process. Memos relating to the emerging themes were used to ensure the researcher had situated his interpretations within the data. To check the validity of the analysis randomly selected extracts of the coded interviews were read by the researcher’s academic and field research supervisors on a number of occasions. In addition, one fully coded interview was discussed by the academic supervisor and the researcher. Attending a qualitative support group allowed the process to be peer reviewed throughout.

## 2.5 Analysis

### 2.5.1 Introduction

This section provides a detailed account of the analysis and details the superordinate themes that emerged from the accounts. These themes were not necessarily the most prevalent within the data, nor were they mutually exclusive from one another and they should not be seen as definitive. Rather, they are the researcher's interpretation of what stood out from within the transcripts. The Table 2 (below) details the superordinate themes, alongside the subordinate themes that converged to create these. Each theme is then expanded upon, and they are exemplified through the use of direct quotes<sup>4</sup> and interpretation. This is followed by a discussion of the overall findings, where the narrative is pieced together to form a meaningful account of the cohorts' experience. In addition, other aspects of the accounts, which did not necessarily fit into the superordinate themes, are looked at.

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<sup>4</sup> Please note, where quotes are used they are referenced against the transcripts (which are provided as an addendum) in the following format: interview number, name of participant, and line number. For example 3, Andrew: 427-428 refers to a quote taken from participant 3, pseudonym Andrew, lines 427-428 of the transcript. All quotes are italicised and indented to make it clear that they are taken verbatim from the transcripts. Interviewer's interjections are capitalised. In the extracts (.) denotes a longer pause and ...denotes missing text.

### 2.5.2 Results

Table 2: Detailing the superordinate themes and the subordinate themes

<b>1. Facing up to Dementia.</b>  Communicating the horror  Injustice  Broken social contracts
<b>2. Challenges to Male Gender Stereotypes</b>  Abnormal activities  Emasculation
<b>3. Issues of Control</b>  Anger and frustration  Impotency  Regaining control
<b>4. Using Psychological Defences</b>  Minimisation  Doing as a defence  Defending against guilt
<b>5. Loss</b>  Loss of person  Isolation

### 2.5.3 Theme 1: Facing up to Dementia.

One of the most consistent themes to emerge from the data was facing up to the dementia. As a long term degenerative condition the meaning of this changed throughout the course of the dementia process and participants were constantly forced to re-evaluate what was happening and what impact it had. Much of what they saw was destructive and they often described how horrific the impact of dementia was.

Mark reflected on the extent to which it had affected his life:

(1, Mark: 300-303)

*“...I think the mental strain on the carer is worse than the physical strain on the carer because you never ever switch off.”*

That never switching off meant never being able to walk away from it and emphasises how the condition invaded every aspect of his life. In Ian’s case the extent to which dementia impacted on him was pointed out by his daughter (who was a nurse and had worked on a dementia ward):

(7, Ian: 362-364)

*“...she says to me ‘the thing is (.) when I finish my shift I walked out of there, your shift never finishes’ which is which is true really you know, I mean you’re there you’ve got it and its and and and and it’s there.”*

Roy described some of the physical changes he saw in Paula and the practical changes they had to make to accommodate this:

(5, Roy: 140-146):

*“...she began to walk with a a her knees bent you know and a it was taking a long time to get her up and down the stairs so obviously the house must have a nice bedroom upstairs and so on you know erm, so what we’ve had to do now*

*is, I've had to bring a couple of beds downstairs and made the dining room into a bedroom."*

Roy's example illustrated how their world had literally been turned upside down and things they once knew as certain, like bedrooms being upstairs and Paula being mobile, were now challenged. Tony also spoke about a world that was turned upside down:

(2, Tony: 567-568)

*"...the outside of the home was mine the inside of the home was Sue's."*

It seems as though the implicit social contract they had, 'this is what I do and that is what you do', had been broken and Tony now had to enter a world that did not belong to him.

Later on Mark was struck by how insidious the condition was and realised that once dementia had taken hold there was no going back:

(1, Mark: 117-122)

*"I mean me first thought is oh she's young yet, there's time for that to be sorted you know if we can manage for ten years that's nothing you know. And before we knew what were happening she started to lose everything."*

The last part of the quote was filled with resignation and made it seem as though things had simply run away from them. Ken saw Mary's deterioration as a more gradual progression, although the ultimate outcome was very similar:

(4, Ken: 201-209)

*"... then slowly it came on that I had to start looking after her more...been doing that for probably five years you know, something like that..."*

As was said earlier, much of how participants described what was happening was dependent on where the person was in the dementia process, and it was interesting to compare these experiences against that of Ian. Whilst Jane and Mary had both been diagnosed with dementia several years prior to the interviews, Pippa was relatively early on in the process, and this perhaps explained why Ian remained hopeful:

(7, Ian: 425-428)

*“Erm I would love Pippa to get better, I know that she’s not going to and Pippa knows that herself. Erm but I think if it stays on this level if it was to stay on this level and not get any worse I think that would be great...”*

It is possible that Ian would get his wish and not have to face the same realisation that Mark or Ken did, but as Pippa had a diagnosis of Alzheimer’s disease it seemed more likely that he would.

For some of the participants there was a real sense of injustice about what had happened. Any hopes or aspirations that they had for the future were now taken from them, and they were left asking the question ‘why us?’

(1, Mark: 121-127)

*“...yeah I sort of thought why now, this is the end of everything we’ve planned for, we’ve just got the children settled and we’ve just started enjoying life and you know everything was going along brilliantly and then the fear is oh no it’s like somebody’s cut your legs off.”*

It seemed Mark was so struck by this injustice that he could only describe what had happened in terms of physical disablement, perhaps the worst imaginable thing for him, and couched in terms that were clearly visible to everyone. This might reflect dementia being a condition that happens from the inside out, offering few visible



clues as to the enormity of what is really happening, rather than the more obvious impairment of losing a limb. Roy also felt an overwhelming sense of injustice and anger at what had happened to Paula:

(5, Roy: 235-255)

*“But I mean we’ve worked right from being married we have never ever had one day where we have been out of work, we’ve never been on the dole as they used to call it or whatever erm until Paula was ill and er you know I’m sure you get people that have never worked that have drunk their money away you know erm and they just get it sort of cheaper than I do and I er you want a fair society but sometimes you do think it isn’t bloody fair why she’s got to spend all her sodding money and you know and have nothing. It did I mean we haven’t got a lot er and it always seems that the very rich it doesn’t matter whatever they do it doesn’t matter because they can afford it. The very poor it doesn’t matter cos they get it free. It’s the ones inbetween the borderline cases like ourselves that’s got that just that little bit more cos you’ve worked hard and you’ve tried hard and you’ve tried to have a good life you’ve tried to do the things that people say you should do you know erm not get drunk every night and and save your money and and try to have a good life and you’re penalised and it sticks in my bloody craw I’ll tell you.”*

Roy clearly felt that they had done what society had expected, they had been upright citizens, adhering to the rules and yet it was them that ended up being punished. This offered another example of the breaking of a social contract, ‘if you do the right things you will reap the rewards’, only not in this case. Roy might have been rueing the fact that they did work so hard for the hope of future gain that never materialised, and wishing that they had had more enjoyment from life whilst they were both able to.

Mark and Jane had also done what they thought was expected of them, worked hard, raised their family, paid their mortgage and had then seen their desired goal being moved out of reach. It is, perhaps, unsurprising that they were left feeling cheated.

#### **2.5.4 Theme 2: Challenges to Male Gender Stereotypes**

As the participants began to adjust to their changed situations they were faced with taking on new roles and responsibilities within their relationships. Many of the couples in the cohort seemed to adhere to more traditional gender stereotypical roles and so some of the tasks the men now had to face, such as cooking and cleaning, were seen as abnormal activities for them:

(4, Ken: 179-186)

*“...but she used to do all the cooking and every everything really, you know I used to do the gardening and things like that but, and she used to say er do you want me to show you how to cook this and this and I used to say no you know you’re better at it than me [laughing], I’ll just eat it. But honestly since she she took ill then I’ve had to learn how to cook...”*

There was perhaps a sense of embarrassment, or guilt, when Ken laughed after admitting that he once took his wife’s cooking so lightly, and it is possible that cooking was a metaphor for the greater loss of her as a person and that he was lamenting the fact that they could never go back to the way it was, when the world was a more straightforward place. Tony also talked about having to take on new tasks:

(2, Tony: 572-579)

*“I tend to do cleaning twice a week on a Tuesday and a Friday...I probably didn’t do it as well as what she did but it’s clean and it’s tidy and people walk in and say what a nice home so (.).”*

It was interesting that he chose not to finish his sentence. Perhaps he wanted to continue to say ‘so even a man can do a woman’s work well if he has to’, much to his own surprise.

It also seemed that some of the participants’ core beliefs, in relation to their position within the relationship, were challenged. There was, on occasion, a sense of unease in the way they described the change over of roles and it is possible that this was due to the participants feeling that they were losing their male identity. Carrying out these new duties, such as cooking, cleaning and caring, was contrary to previous experience and expectations and this challenged their beliefs as to what the man’s role was. Once they began to question their gender role it appeared that some of the participants were left feeling emasculated:

(3, John: 615-619)

*“No your roles change your roles do change you know it feels messed about er the husband and wife the husband does all the heavy work the wife does the cooking the cleaning you know...”*

What John perhaps implied but did not overtly say was ‘but now things are different and I do the woman’s work’ and this broke the social contract they had. Without overtly acknowledging this emasculation John goes on to defend his new position by positing himself as a man who can cope rather than one who cannot:

(3, John: 622-627)

*“...taking over all the roles that wasn’t so bad, but there’s a lot of men out there who are still of the old school ‘wife where’s me dinner’ and if they had to do it they’re gonna be real shocked because of that attitude and there’s still attitudes out there I can tell you.”*

In doing this he is perhaps trying to convey the message that even though he now does the woman's work he is still a man. Kevin was no longer sure what was expected of him in this new role. The sense of certainty he once had about what Erica required had now disappeared, leaving him feeling lost:

(6, Kevin: 77-79):

*“...I tend to feel I've got to walk away, I didn't used to, I've tried to help her and the more I helped her it got worse...”*

Perhaps this change of role, from more traditional male stereotype to 'new man', was something that took more time than the participants had. As was stated earlier dementia is a progressive process and it sometimes seemed that every time the participants thought they knew what was expected the goalposts were moved once again.

### **2.5.5 Theme 3: Issues of Control.**

Much of what emerged from the data revolved around issues of control; whether that was with regard to losing control or trying to regain control. Once it was realised that there was something pathological occurring participants started to feel a loss of perceived control. Services became involved and the couples were faced with alien situations and they were often excluded from the processes going on around them. As the earlier quote from Roy (140-146) illustrated, dementia really did turn people's lives upside down and many of the things they held as certain were now brought into question. This left them frustrated or angry and, at times, there was a palpable feeling of impotence about their ability to influence their circumstances. Ian was left feeling as though he and Pippa were unimportant and he voiced his frustration at their treatment:

(7, Ian: 113-117)

*“...six to eight weeks went by and I hadn’t heard anything from social services so I rang the social services and erm she said erm that Pippa wasn’t a priority, there was a lot more people with with with a priority. Er Pippa Pippa wasn’t a priority with with what she got they’d got other priorities but we were on a list.”*

The final part of the statement, ‘*they’d got other priorities but we were on a list*’, appeared to be dismissive of them and it is clear it left Ian feeling angry that they should be treated this way, and with a sense of impotency at his ability to affect the situation. Roy spoke about the loss of control he felt at having carers come into his home:

(5, Roy: 173-178)

*“...we’ve got the carers coming in which is not ideal erm and if they’re not careful er we’ve spent a lot of money having doors and things put on and they push the wheelchairs into the doors and all sorts.”*

When he talked about how much money has been spent on their home and the damage these outsiders had caused he might also have been speaking metaphorically, with the carers representing the dementia that had come uninvited into their lives and wrought damage on the thing that meant most to him, Paula. John was left feeling as though he was the only person who did not know what was happening in his world:

(3, John: 119-123)

*“And he [the hospital specialist] looked at the notes and said ‘yeah it’s obvious’ you know and that’s through I mean just reading the notes, it were obvious that all these other people never said a bloody word to me...”*

The final part of his statement illustrated how much it felt outside of his control and how impotent he was to control the situation. Everyone else knew other than him, all the people that needed to know, and yet he and Tracey were the ones that were directly affected.

This feeling of anger aimed at the professionals involved was not uncommon and it was also apparent with regard to the input people received. Ken had tried to do his best for Mary and was then left feeling betrayed by the very people who were supposed to be there to make things better:

(4, Ken: 309-319)

*“When she went into hospital she had a pressure sore that was probably at the most the size of er a five pence piece that was just a surface pressure sore and I used to put a dressing on it and she had a little bit that looked like a bit of dry hard skin on her heel and they said that was the start of a pressure sore, I didn’t realise that you could get them on your heels. But when she came out of hospital I was well astounded at what these pressure sores were like, they she’d got one on both heels and they were just her heels were just black.”*

He sounded almost despairing when he remarked that *“her heels were just black”* and perhaps there was an element of guilt on his part for having trusted someone else to look after her. Following a failed suicide attempt by Sue, Tony’s anger towards those who were supposed to be helping her was obvious:

(2, Tony: 110-118)

*“The following day we had the social worker on call coming out and assessing people, they came out and asked the same questions we went through the previous night, they hadn’t picked up the notes from the hospital*

*at all and I was pretty disappointed about it, in fact I was pretty angry. I thought...you can get out of my home because I'm not prepared to speak and go through the same questions, it was winding Sue up and I wasn't prepared to put up with it."*

The way in which he railed against the social worker seemed to mask his frustration at not being able to protect Sue himself, and there was a sense that someone should have been doing something.

There were also examples of participants attempting to regain control of a process that often seemed to be beyond their influence. Kevin found that by gaining knowledge he increased his sense of control:

(6, Kevin: 159-162):

*"...I've gone through most of the books and to get information because I needed it to find out you know different things and what were going to happen and so that were very helpful..."*

During Roy's recounting of his story it became apparent that he had now developed his knowledge of medical matters pertaining to Paula's condition and was able to 'speak the language':

(5, Roy: 269-271):

*"Now in this process or whatever we've found out that she had hydrocephalus. Now whether it was hydrocephalus right from the start and not infarction we're not sure."*

It is interesting that Roy used "we've found out" collusively as if to say 'I am now part of this world of medical investigations and diagnosis'. Taking on the language of the medics allowed him to regain some semblance of control, and to play a part in a

process that was usually thought to be beyond the understanding of non-medical professionals. In a similar fashion Mark used the carers group as a way of regaining control from the professionals:

(1, Mark: 154-159)

*“The [carers] network is closest, we just help each other. If we’ve got a problem we text each other, we phone each other, we meet people there. And we discuss it and somebody might say I don’t know about that but I know a man who does.”*

This suggested a feeling of strength in unity for those who *really* knew what it is like to live with dementia. John also supported this idea of ‘lived’ knowledge being better than that of the professionals, but was more outspoken in how he conveyed his feelings:

(3, John: 766-779)

*“...some of the professionals when they talk about understanding how you feel they don’t understand about living with it twenty-four seven. They say I know what your background is but quite frankly if you’ve never done it you ain’t got a bleeding clue, that’s quite clear and that’s why the carers group is good cos carers talk to carers and when somebody says somebody is being traumatic and they’re having a right time twenty-four hours a day you can nod back to ‘em and they understand that you understand. But somebody who works in an office and then comes out to see you and says oh I understand, not with dementia they haven’t got a bloody clue (.).”*

In attempting to regain control these men were able to challenge the feeling of impotency and reassert their own ability to manage what was happening. It also restored their belief that life could be controllable.



#### 2.5.6 Theme 4: Using Psychological Defences.

Many of the participants in this study were faced with a change of circumstances that was almost too horrific to contemplate, and it was not, therefore, surprising that they used psychological defences to try and protect themselves against these changes. Initially some of the participants tried to minimise what they were seeing. By making difficulties seem like everyday occurrences they were able to pass them off as non-pathological:

(1, Mark: 21-24):

*“But I mean, after all, we all have minor lapses of memory, where we forget what we’ve gone into a room for, or what we’ve done.”*

By explaining Jane’s difficulties in these terms it seemed that Mark was almost inviting the researcher to reassure him that any memory lapses he might have had were normal and not a result of anything more insidious. Mark continued to explain that it reached a stage though where he could no longer account for Jane’s difficulties in terms of everyday forgetfulness and they were forced to confront the situation:

(1, Mark: 44-47)

*“...then we got to the stage eventually when we asked for more detailed investigations. We thought something else was wrong and the GP said ‘I suspected something else was wrong but unless someone tells me I don’t know’.”*

Mark pointed out that even the professional, whose job it was to identify such difficulties, missed what was really happening. This could have been to assuage feelings of guilt at his previous minimisation of Jane’s difficulties, and to offer an explanation for why he did not act sooner. Roy was also forced to face up to Paula’s deterioration when his extended family was there to witness what was happening.

Paula had run a café for most of her working life and was well versed in serving food for people and yet on this occasion she made a fundamental mistake that could not be ignored:

(5, Roy: 13-16):

*“...Paula was cooking in the kitchen with our daughter and she forgot where she put the turkey on the plate and all sorts of things. So of course at that point we said there is something not right.”*

Roy was able to collude with his daughter and it is possible that he needed that third party to help him see what was happening to Paula.

It has been evidenced that male carers use different coping styles to females (e.g. Papastavrou *et al.*, 2007), and many of the men in this cohort used ‘doing’ as a way of evidencing their ability to cope. By showing the world that they were managing the situation they protected themselves from outside interference and from what was perhaps their ultimate fear, that their wife might be taken away if they could not cope. Like Roy earlier, Kevin displayed his expert knowledge, on this occasion as a way of demonstrating his coping skills:

(6, Kevin: 4-7):

*“Erm(.) I was expecting it meself cos her mother went the same as Erica, so I’d experience of seeing her mum and when they did tell me I I was shocked but I I sort of understood, you know what I mean erm (.)”*

Kevin chose to pause at that moment and it is possible that what he was saying to the researcher was ‘...so I know as much as you. Therefore, you don’t need to worry about my ability to look after my wife’. Later on he again demonstrated his ability to adapt and cope:

(6, Kevin: 95-98):

*“...I learnt how to cook dinners and [laughing] I’d done them before, beans on toast or things like that, but but a real proper dinner, vegetables and whatever, but yeah I have it done it before but really more now yeah I do everything.”*

Kevin showed that he had previous skills that he had built on to such an extent that he could do ‘everything’ that was needed.

(6, Kevin: 99-106)

*“...I’ve had experience of doing that when I were when I used to go camping when I were you know a youngster and (.) I mean it helps you through. If you hadn’t done anything like that I don’t know what it’d be like, if I’d never done anything before oh dear [laughing] you know. I mean there’s people like that isn’t there, there is some men like that, wives’ have looked after them and but er I’m lucky I I have done bits and bobs so...[end of sentence]”*

In this quote he used social comparison to show how well equipped he was to deal with the new challenges that he now faced, again emphasising his own ability to cope. Again he left his sentence unfinished and he was, perhaps, reinforcing his message to the researcher; ‘I don’t need anyone else to help me cope with this’.

The issue of guilt was apparent in many of the transcripts, although it presented in different ways. Some of the participants seemed to feel guilty that they did nothing to protect their wives’ from the dementia, even though this was outside of their control. This was exemplified by Mark and his willingness to assume the responsibility for not identifying Jane’s dementia:

(1, Mark: 60-67)

*“...no comeback on anybody because none of us really suspected what was wrong initially/*

*[INT] SO YOU DON'T THINK THAT ANYBODY MISSED THIS ALONG THE WAY?*

*/no no no no no. I don't I don't blame anybody for missing it, if I blame anybody I blame meself.”*

John seemed to be inviting the interviewer to reassure him that it was not his fault he did not have more awareness of dementia:

(3, John; 253-258)

*“The early stages I really didn't know about the illness you know and I tried to find out as much as I can, but unfortunately my education is not great I'm not a big reader. I can sit down and have a look and I couldn't sit down and read a book, no. Do you see what I mean?”*

Perhaps they felt that men should be able to protect their wives' against the dangers they faced, and that they had failed because they had been unable to pre-empt the dementia.

At other times it was a case of feeling guilty about some of the actions participants took due to the changing face of the dementia. From the outset, even before the diagnosis was received, Mark felt guilty about what he wished on his wife:

(1, Mark, 10-14)

*“...and there's me hoping and praying that it's anything bar dementia, which is a terrible thing to do really, wishing something like a brain tumour on your wife, but at least it's curable.”*

His belief that a brain tumour was curable only highlighted how negatively he viewed the alternative possibility that it might be dementia. Roy spoke about the other end of

the time scale, when the dementia had progressed so far that there was little of the Paula he knew left:

(5, Roy: 261-264)

*“...now at the later stages of dementia I can’t converse with Paula and she doesn’t know what I’m talking about. Most of the time, well most of the time she doesn’t know who I am...”*

It seemed almost as though Roy was excusing the fact that he no longer made the effort to talk to Paula, even though on the occasions he did he got little in return. Ken assumed a sense of guilt over the action he took when Mary’s behaviour became unmanageable and potentially dangerous:

(4, Ken: 105-110):

*“...she didn’t know right from wrong and she wanted to walk and often go out and walk so as in the first place I used to let her go but then eventually I had to stop her doing it and I had to make sure she was locked in because I didn’t know where she would have wandered off to you know.”*

By finishing his statement as he did Ken invited the interviewer to collude with his action, possibly as a way of assuaging his guilt. John also felt the need to justify his actions:

(3, John: 703-716)

*“...she just got up from that seat picked up a glass walked over to the telly and just poured coke straight into it bang I said well that’s bloody marvellous then ain’t it or words to that effect and that was it she just then started throwing things around and it started with small items she went in there she got er an ashtray because she used to smoke then and she just smashed it with one hand*

*and as I say er (.) they'd been other behaviour problems before but I as I say you can't restrain her I actually put her grabbed her put her in the chair once and she just got up and then did it."*

John contradicted himself; firstly stating that "...you can't restrain her" and then demonstrating that he tried to do just that "...I actually put her grabbed her put her in the chair". This perhaps highlighted the internal struggle he had over how much control he should take over his wife and what was reasonable in terms of looking out for her best interests. Mark also struggled with this issue of having to take control: (1, Mark: 316-322):

*"So I do find the control side very, very difficult to be honest because like I say I'm not a control freak, I'm not out there to run somebody's life. Jane's had her own choices on what she wanted to do and now I'm having to make the choice for her it feels really alien."*

Ken seemed embarrassed at having to admit that he sometimes felt frustrated with his wife, stumbling over his words until finally he said what he wanted to convey:

(4, Ken: 465-468)

*"I'll look after her and it's not really bothered me at all, it's not, I've not found it a problem, I've been, you get frustrated at times when she won't eat quickly and because you can't rush her to eat."*

Mark appeared to want to justify why he needed Jane to have respite care:

(1, Mark: 605-610)

*"...we do have bad nights, we have bad days and bad nights. But yeah I don't feel totally worn out now, now I've started doing respite. I did before. I wouldn't admit it but I was totally physically, mentally and emotionally I was a wreck..."*

Kevin's guilt seemed to be around him having to acknowledge what the future held for them:

(6, Kevin: 159-165):

*"I think you need to find out information to prepare yourself for anything that's going to happen so (.) it's not very nice but I think it's something you have to do."*

In assuming guilt and justifying their actions these men seemed to be suggesting that they had behaved in ways that were unacceptable, yet what they described was often understandable given what they were faced with. Perhaps they needed reassurance that they had 'done the right thing' and were hoping that the researcher could provide this.

There was also evidence of participants projecting guilt onto others, perhaps as a way of exonerating themselves for missing what had happened. By apparently putting their faith in the medical profession the participants were ceding responsibility to those that were supposed to know, and if they then failed to identify dementia it was not surprising that the participants had done too. In many cases this belief that they could not be expected to know if the medics got it wrong was reinforced by their wives initially being diagnosed with functional mental health problems such as anxiety and depression.

(2, Tony: 47-53)

*"We were seeing a Consultant at the [hospital] at that stage and she said well you know we've tried all these at the same time because it was depression and you know she'd already explained to us that there was always electrolysis [sic] as a principle to knock the depression on the head and Sue would come back,*

*so we always had in the back of our minds there's something there that if these medications just didn't work, we could look at this facility and bring Sue back to how she was in October 2004."*

In pointing out that someone as eminent as a hospital Consultant had missed this dementia Tony was excusing the fact that he had not known what was happening to Sue. John and Tracey had a similar experience:

(3, John: 48-53)

*"...she was being treated for mental illness er not mental illness for the anxiety and depression er trying to treat her and I kept saying there's more to it than anxiety or depression she was forgetting things simple things but there were so many of them happening erm (.)"*

John, however, highlighted that he knew there was more to it, suggesting that he was more knowledgeable than the doctors but had been ignored. This placed the guilt at having let Tracey's dementia develop unnoticed with the health care professionals rather than with him.

### **2.5.7 Theme 5: Loss**

Loss was spoken about throughout the interviews and took many different forms. Many of the participants described the deterioration of memory and cognitive functioning, but what they were really talking about was the loss of the person they knew:

(4, Ken: 11-19)

*"...Mary was a teacher and...she was very good at English and spelling and things like that and she used to write lots of letters and she did er calligraphy and stuff that sort of writing and she got that she was asking me how to spell things*



*'how do you spell so and so' and I thought you don't have to ask me that I have to ask you that...'*

Ken highlighted Mary's skills as a way of demonstrating the enormity of the loss and later on this contrasted against what he saw her become:

(4, Ken: 76-78)

*"(.) she changed, she'd never been a nasty person or anything like that and she never was but she started in my opinion not recognising right from wrong..."*

The school teacher he once knew, a woman charged with teaching children right from wrong, was now unable to even do so herself. Deterioration in cognitive functioning also meant that meaningful communication eventually disappeared:

(6, Kevin: 170-172)

*"Er communication I think, I'm missing that one-to-one cos we've been married 40 years er I'm missing that I think that emotional you know what I mean and that's quite hard..."*

This seemed to leave Kevin pondering what was left of their relationship once the intimacy had gone. Loss of the person also applied to the participants themselves and Mark reflected on his feeling of redundancy:

(1, Mark: 638-645)

*"...and it does it feels like I don't know as though your purpose has been taken away really cos its what do you do you know, it's a real strange feeling. I think it was summed up by my sister when she cared for her husband for ten years and on the day of his funeral they turned round and said how do you feel and she said redundant."*

Mark had already faced up to redundancy of role once when he had left his job to become Jane's carer, now he was faced with the prospect of having to redefine himself for a second time.

Having witnessed the loss of the person closest to them, participants' sense of isolation was further compounded by the loss of other significant relationships and the difficulties they had finding suitable services.

(7, Ian: 381-387)

*"Pippa's elder sister comes perhaps about once a fortnight on a Friday I mean she's just retired so it probably gives her a bit more time but everybody seemed to (phew) back away go (.) you know and I said I forget what I said to her I said Pippa's got Alzheimer's not bloody leprosy you know and that's that's that that's how I felt that's how I felt I mean that's I felt that everybody was sort of backing off."*

Ian obviously felt let down by those he might have expected would help. When he said to Pippa's sister that she had "...Alzheimer's not bloody leprosy..." he conjured up images of leper colonies and complete isolation and was, perhaps, telling her that he needed help to bear this incredible loss. Similarly Jim found that people he once considered were closest to them had disappeared:

(3, Jim: 541-560)

*"...but the older friends and family very much family we'd lost. Tracey's sisters haven't seen her in over two year. They it was just before Christmas brother-in-law come down with present and they'd been to see her in September they'd been to see her in March wedding anniversary and her birthday (.) and they said that erm they were bringing the cards down and I*

*says oh well it's Christmas you're gonna go and see her then are you you know and they says you can tell the sisters and I said brother-in-law you're brother-in-law you're not Tracey's relative only by marriage I says it's not your responsibility but her two sisters both can get to that place very easily you can tell them I'm disgusted and ever since then we've never heard or seen a birthday card, Christmas card not contact whatsoever they haven't even been to see her or enquired about her."*

This could be seen as a metaphor for the disappearance of a life they once had. Not only was Tracey leaving him, but also her family and their friends and Jim would have to start again. Ken highlighted the almost paradoxical sense of isolation created by the involvement of services as he was aware of their presence watching on whilst still being left feeling as though he had to fend for himself:

(4, Ken: 381-387):

*"...once they know about you they do er (.) you do get a little bit more help but it's not I I think a lot of the help you don't you don't know what you can get and there's nobody tells you, nobody says oh you've got so and so wrong with you or your wife's got this wrong with you you can have this or this you know."*

There was a sense of conspiracy when he talked about "*nobody*" telling him what to do. It raised the question of who Ken wanted to take control and contrasts against the issues of lost control that were highlighted earlier in the analysis.

## **2.6 Discussion**

### **2.6.1 Discussion of the Analysis**

It was widely acknowledged within the dementia care literature that the caring role was detrimental to psychological and physical well-being (e.g. Katon *et al.*, 1982; Papastavrou *et al.*, 2007). However, there seemed to be little attempt to explore what it was about being a carer that it made it so damaging. The aim of this study was to explore the way in which men experienced and perceived their role as the carer of a spouse who developed a WAD. IPA allowed the researcher to identify the individual phenomena that were important to the participants and to offer interpretations of the meanings of these phenomena. It was hoped that this exploration of individual experience would help to develop some insight into why this role is perceived as being so burdensome. The emergent themes will be further discussed and linked to the existing research.

### **2.6.2 Discussion of the Themes**

#### **Facing up to the Dementia**

Although it was the spouses who were diagnosed with dementia its impact had a profound effect on the participants. Their narratives highlighted that there was little positive about the dementia process. When they described what they faced it was often portrayed as a dehumanising and horrific experience for all those involved. Due to the degenerative nature of dementia the challenges participants faced seemed to change throughout the time they spent caring, making adjustment difficult. Furthermore, several of the participants reported how hard they found it to ‘switch off’ psychologically from being a carer, even when they were away from their

spouses. This resulted in carers being faced with ever changing demands over a prolonged period of time, without being able to disengage from the role. This could be viewed in terms of Kramer's (2000) wear and tear hypothesis, which suggested that there was a correlation between the length of time spent caring and higher levels of perceived burden.

### **Challenges to Male Gender Stereotypes**

The existing research highlighted that men reported lower levels of perceived burden than women (e.g. Kaye & Applegate, 1990; Hooker *et al.* 2000). This was generally explained in terms of men adopting more pragmatic ways of coping and females using emotion focused coping styles. What it did not generally address, however, was the effect that becoming a carer might have on male gender role identity. This was an area that might have been viewed as particularly pertinent to this cohort as they were all of working age when they took on the caring role. In addition, all of the couples seemed to adhere to stereotypical gender roles, where the men reported having responsibility for the heavier/manual tasks such as gardening and the women cooked and cleaned.

Once the wives were no longer able to fulfil their traditional duties these had to be taken on by the husbands. In addition, some of the participants had to give up work to become full-time carers and this meant they had to relinquish their former status, adjust their expectations and learn new skills. This resulted in some of the men feeling that they were 'trespassing' in a world that was not theirs' and there was an underlying sense of emasculation. This tied in with the findings of Addis and Mahalik (2003) who suggested that men who held traditional ideas of masculinity were more affected by the loss of this status.

## **Issues of Control**

A theme that consistently emerged was loss of control. All of the participants alluded to this and it seemed to play a major factor in their negative appraisal of the caring role. For many of the cohort dementia almost literally turned their worlds' upside down and once professionals became involved in trying to diagnose and treat the difficulties it seemed to some that they were no longer part of what was happening. As the dementia progressed there followed a process of constant adjustment to the new challenges they were faced with and this made regaining any semblance of control extremely difficult. Some did manage this, mainly through the acquisition of knowledge or expertise. This was demonstrated by those participants who sought out information on dementia, started using medicalised language or became heavily involved in carer's groups. This supported the findings of Graham *et al.* (1997) who had suggested that those carers who sought out information generally reported lower levels of burden. Also McFarland and Sanders (1999) who identified information seeking as a specific coping style adopted by males caring for someone living with a dementia to help re-assert control over the condition.

## **Using Psychological Defences**

A variety of psychological defences were employed in order to protect participants from the enormity of what was happening. Initially they tried to minimise what they saw and this seemed to serve a dual purpose: firstly it enabled them to dismiss the lapses in memory and loss of skills as non-pathological and, therefore, non-threatening to their lifestyles; secondly it protected them from the idea that if what they were seeing was their wife developing a degenerative pathological

condition, then perhaps their own lapses of memory and loss of ability were also due to something more insidious than normal ageing.

The carer literature frequently suggested that men adopted more pragmatic ways of coping (e.g. Kramer, 1997) and this was evidenced by some of the carers in this study. They described the ways in which they had been able to adapt to new roles and the existing skills they had drawn on. By showing how they were able to meet the new expectations they seemed to be saying that there was no question about their competency. This defended them against the threat of being seen as unable to cope with the demands they faced. For some of the participants there was an underlying sense of guilt in what they said. This guilt either seemed to be focused on the fact they had not realised the severity of the problem earlier, or that they had been unable to protect their wives from the dementia. This might again tie in with the idea of traditional male stereotypes that was previously mentioned. If they held the view that they should have been able to protect their wives from harm then they had failed in their role as a husband causing them to feel guilt. In some cases the men readily assumed this guilt, whilst at other times they projected it on to others.

## **Loss**

Of the five themes that emerged from the analysis perhaps the most compelling, in terms of the overall narrative, was that of loss. This often seemed to be at the heart of what was being said, whether it be in terms of loss of the person, loss of lifestyle or loss of imagined future. Through their interviews it was evident that many of the participants were struck by the injustice of what had happened, and some questioned why it had affected them in particular. This feeling of unfairness might have been exacerbated by the fact that dementia has not been linked to lifestyle

factors in the way that, for example, lung cancer or coronary heart disease had been and so its onset was seemingly random. It was seemingly compounded by the stage of life that the majority of couples had reached. They described how they had worked hard, raised families, paid off mortgagees and had been looking forward to enjoying the fruits of their labour, before having it all taken from them by dementia.

### **2.6.3 General Discussion**

The overall feeling of the accounts was that the participants were experiencing a huge, multi-faceted loss: of the person they loved; of the person they were; of the lifestyle they had; and of the future they aspired to. It seemed that this was even more difficult to bear than the day-to-day challenges participants were faced with and it engendered a sense of longing for what should have been in an ideal world. The 19<sup>th</sup> century essayist William Hazlitt (1778-1830) perhaps captured the sense of this best with his remark that; “Man is the only animal that laughs and weeps; for he is the only animal that is struck with the difference between what things are, and what they ought to be”.

What was not necessarily evident within the themes was how much participant’s accounts were influenced, and how their needs changed, depending on where they were in the dementia process. Three of the spouses had been diagnosed with the condition less than two years prior to the interviews and two of these were still at work. The remaining spouses had been diagnosed between four and eleven years earlier and all of these had stopped working (although it should be noted that some described this in terms of having taken early retirement and one had since returned to work as his wife had gone into full time nursing care). Those carers who were relatively new to the role still held out some hope, if not for a cure at least for



the condition to remain manageable. Whilst those who had cared for longer seemed to have become resigned to the way things were likely to turn out. All of the participants described similar stages that they had passed through or were in the process of passing through and they spoke of having different needs at different times.

These findings mapped closely onto Pearlin *et al.*'s (1990) model of caregiver stress. The model reflected the dynamic nature of the experience and could help to explain the individual differences, in terms of how well the men coped, seen within the group. The Primary stressors in the model were described by the participants in several ways, including the behavioural difficulties they were faced with, having to take on domestic tasks within the house that were previously seen as the realm of the wife and the physical care that they had to provide. Whilst these were undoubtedly difficult to adapt to they did not appear to be as important to the cohort as the secondary stressors, such as the disruption to work and social relationships. Perhaps this was due to the fact that all of the group were of working age and might have been expected to be in employment, or have more in the way of social activity than an older carer cohort. Many of the men had given up work and relinquished previously held roles to become carers and several had started to identify with this as their primary role. This shift was also described within the intrapsychic element of the secondary stressors of the model, and it perhaps highlights the importance of social context on the perception of what is stressful within the caring role.

A final point worthy of note was that several of the participants reflected on how it had been helpful to share their accounts with the researcher. The entire cohort described periods of low mood or clinical depression and for some having the opportunity to confront the system (in the form of the researcher) that had frustrated them or let them down might have been cathartic. Others stated that they wanted to

share their experiences in order to help those who would be confronted by the same difficulties in the future.

#### **2.6.4 Limitations of the Study**

In line with IPA methodology a homogenous sample was sought. In order to achieve this, the researcher approached specialist WAD services within a single NHS Trust. The fact that these participants were known to services, and that many of their wives received some kind of day care, was likely to have influenced how they perceived their role. This made generalising findings across other groups very difficult and future research might benefit from broadening the sample. IPA methodology does not require rigorous inclusion criteria and although the homogeneity of the sample has been alluded to it became apparent during the analysis that some of how the role was perceived depended on where in the dementia process the spouse was and how long the participants had been caring for them.

No pilot study was conducted prior to the research taking place. This was mainly due to the limited number of potential participants available within the NHS Trust where the research was conducted. Had it been possible to do so the researcher might have developed the semi-structured interview schedule further, and included areas that were not originally touched on, such as the effect on intimate relationships. It may have been beneficial to check the researcher's emergent themes with the participants as a means of validation. However, this was not done due to the time constraints of the research project.

The researcher's standpoint was to accept that the accounts given by the participants were true to them. However, it must be noted that many of the participants were being asked to reflect on dynamic events that had happened over a

number of years and it is likely that this will have affected their perception of these what had happened.

### **2.6.5 Clinical Implications**

The statistics relating to the increasing incidence of dementia would suggest that more people will be expected to provide informal care. If services are to expect people to continue offering the level of input they do it is important that their needs are understood. This study highlighted loss of control as a major factor in the carers' negative appraisal of the role. It might be beneficial then for those involved with diagnosis to signpost where appropriate services are available. In relation to this study, the Trust had specific WAD services and it would seem correct for people to be directed towards them. However, this was not current practice and often participants only found out about these services through secondary sources. It was also apparent that peoples' needs changed over time, so it would be useful for their requirements in terms of information, support and input to be re-assessed on a regular basis. This could be achieved through ongoing contact with services.

Given the negative way in which participants generally spoke of living with dementia it was unsurprising that they described periods of low mood and depression. Whilst some had been prescribed medication none of them had routinely been offered therapeutic intervention. Although this might not be appropriate in all cases the comments made by several of the participants, regarding how useful it had been to share their stories, might suggest that it would have been beneficial for some people to have access to psychological therapies. Due to the dynamic way in which their needs changed throughout their time caring this could be offered at various times.

### **2.6.7 Future Research**

By its phenomenological nature IPA does not seek to generalise its findings across populations. It might be useful then to carry out similar studies looking at other carer groups, such as female carers, non-spousal carer and older carers. This might allow for some comparison of the emergent themes and enable services to tailor interventions appropriately. It might also be useful to look at similar carer populations using different qualitative methodologies, such as grounded theory, to produce a fuller picture of the role at a more individual level.

### **2.6.8 Conclusion**

The current study set out to explore the way in which men whose wives developed a WAD experienced and perceived their caring roles. It was found that they were often frustrated with the services that were there to help and this led to feelings of anger and impotency. Changes in their traditional male roles left some of the cohort feeling emasculated. They identified loss of control as the major factor negative factor in the way they appraised their role and information and knowledge seeking were used as means of regaining control. The dementia process was described in dynamic terms, with carer needs and appraisal of the role changing as the dementia progressed and this could be described in terms of the caregiver stress model (Pearlin *et al.*, 1990). The overriding feeling from the narratives was that of loss of what might have been.

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### **Section 3.0: Critical Appraisal**

A Qualitative Study of the Way in Which Male Carers of Spouses With a Working Age Dementia Experience and Perceive Their Role.

Word count: 3,467.

### **3.0 Critical Appraisal**

#### **3.1.1 Origins of the Study**

The idea for this research study arose from my clinical work and my own personal experience. During clinical psychology training I was on placement in an older adult community team and much of the service's work was focused on the assessment of people who developed dementia. One of my cases was to carry out a needs assessment for a 59 year-old man who had developed a working age dementia (WAD). Prior to this my only real knowledge of early onset dementia was through working with people with Down's syndrome. Having met with the client and his wife I was struck by how much impact the condition had on them, their relationship and their circumstances. I was also surprised at how difficult it was to find appropriate input and services to meet this person's needs.

In addition to this case, my choice of research project was influenced by my personal experience of caring for my elderly father. He had become physically unwell and appeared to be in the early stages of dementia (although this was never formally diagnosed). This necessitated a high level of care to ensure his safety and well-being. I felt that this allowed me some first-hand insight into the difficulties associated with providing such care on an informal basis, negotiating complex medical and benefit systems and realising the impact that a debilitating condition can have on the person themselves and those around them.

My own clinical practice is informed by systemic and narrative approaches. I believe that psychological well-being is influenced by the stories that people hold about themselves and their difficulties and also the way other people perceive those narratives. This epistemological standpoint, coupled with my special interests, led me

to want to conduct a research project looking at some aspect of the experience of familial carers in WAD.

### **3.1.2 Planning the Research**

In preparation for conducting the study a literature search was carried out to inform my initial research proposal. This highlighted a lack of qualitative research focusing on the experience of those caring for someone living with a dementia in general and WAD dementia in particular. To further focus the study I decided to look specifically at the experience of male carers. I felt that by combining these areas it would bridge some of the gaps in the existing corpus of research. By developing an understanding of how the role was experienced it might help to inform future service provision in terms of what would be helpful for carers. This was particularly pertinent in light of the 2006 National Institute for Health and Clinical Excellence (NICE) guidelines for dementia care, which highlighted that younger people with dementia had specific needs and that specialist services should be developed to help meet these needs.

Based on this I looked for a qualitative methodology that would allow me to examine the individual experiences of the participants so as to gain the insight that I wanted. I initially considered using grounded theory (Charmaz, 2006). However, having read up on the methodology in more detail, and thought about in context of my study, I realised that it did not meet my requirements. I wanted to focus on what it was like as a carer and what made the role so burdensome. Following discussion of this with my academic research supervisor it was suggested that interpretative phenomenological analysis (IPA; Smith *et al.*, 1999) might be better suited to my sample population and what I wanted to achieve from the research. This allowed me

to start to formulate my research question more fully, to develop my interview schedule and to have an idea of the number of participants that I would need.

### **3.1.3 Recruitment of Participants**

Following the submission of my research ethics form I came across my first unanticipated obstacle in terms of operationalising my project. As part of my ethics application I had to gain approval for the study at a local level from the NHS Trust's Research and Development department. Due to new national guidelines relating to conducting research within the NHS the Research and Development department involved was being re-structured and had cut the number of staff working there. Unfortunately this meant that at the time I was ready to submit my application to the department there was no member of staff available to process it and I was unable to gain the necessary clearance for five weeks. I found this delay to be extremely frustrating and due to the time constraints inherent with conducting a research project as part of clinical psychology training I had real concerns that my research would not be achievable within the time frame I had.

Once approval for the study had been obtained I began contacting professionals who might be able to help in the recruitment of participants. I was aware of how specific my participation group was, male carers whose partners had developed a WAD, and realised from the outset that this would not be easy. Nevertheless, I remained hopeful of being able to conduct my study within a single local NHS Trust that had a day service for WAD and a social worker who worked with the client group. Following a meeting with the head of the day service and the social worker I was optimistic that I would be able to approach a minimum of 12 potential participants. It soon became apparent, however, that for a variety of reasons

many of the potential participants did not want to take part in the study. I had also underestimated how difficult the process of contacting participants through a third party (i.e. the social worker or the day service) was. I would sometimes spend several weeks trying to contact either the professional or the potential participant. At this stage the doubts as to whether I would be able to recruit my required sample and collect my data in the time I had available resurfaced.

In total I managed to recruit four participants from this source, which left me with a shortfall in the number of people I needed to conduct my study. In fact settling on how many participants were needed raised some concerns for me. In their chapter on carrying out IPA research Smith and Osborn (2003) suggested that for a project such as mine five or six participants was an adequate number. However, the university was suggesting that I needed to recruit a minimum of eight participants. Given that my only known source of participants had yielded four people willing to be involved I now had to consider whether I needed to find another NHS Trust that had a WAD service that I could access. This would have meant a further research ethics application as my approval was for a single site study and this would probably have resulted in the project not being completed on time. This was extremely disheartening, it seemed that there were so many factors that were outside of my control that I wondered if it was even worth pursuing the study and an entry from my reflective diary from that time read “It just gets so frustrating, people not doing what they say they will, then being told this by one person and that by another. I wonder if I should re-think what I’m doing before I get too far down the line and can’t turn it round.” In retrospect I feel that I should have shared my concerns at the time with my field supervisor. However, I felt that doing so would have been tantamount to saying ‘I’m

not capable of doing this' and having spent over two years building towards the research study I did not feel this was an admission I wanted to make.

Fortunately, whilst arranging one interview a participant asked if I had also contacted the WAD service based in the North of the Trust. This came as a surprise to me as no one else I had spoken to had mentioned that there was another day service provision within the same Health Care Trust. Nor had I had found any mention of it during my preliminary investigation into the feasibility of the study. I realise now that I should have been more thorough when looking for specialist provision as a good internet search produced the contact details of this service. After speaking with the head of this service, who was extremely helpful, I was able to recruit another three participants, meaning that I had seven in total. This was a great relief and restored my belief that the project was achievable.

#### **3.1.4. Data Collection**

All of the participants had an emotive story to share that tended to centre on loss and injustice and many of them were angry about what had happened. This made some aspects of the interviewing process quite difficult and I often left a session feeling drained. However, it was these stories that interested me most and I was impressed by the participants' ability and willingness to be able to recount what had, generally, been a very negative experience. There were also times when I felt as though I had opened up wounds that they had tried to heal. This made it hard to walk away from the interviews having seemingly offered nothing in return, although some of the participants remarked that the process of recounting their story had been useful to them. For all the difficulties though listening to the stories was the most rewarding part of the research process.

I successfully completed the first of my interviews in December 2007. This was, however, only after I had had to abort my initial attempt at interviewing the participant due to difficulties with the digital recorder that I was using. Fortunately the participant was sympathetic to my plight and we rearranged the interview. Having had to stop the interview and rearrange it I was left feeling quite un-professional and I questioned my ability to conduct the interviews successfully. However, the rearranged interview went extremely well and this restored my confidence. In fact I feel that in some ways the difficulties with the recorder allowed me to build a better rapport with the participant and this resulted in a better interview. For subsequent interviews though I ensured that the recorder was fully functional and I took along a cassette Dictaphone as back up. Contrary to my earlier concerns I was able to complete all of my interviews and have them transcribed by April 2008. This left me feeling confident that the study was now achievable in time for my deadline.

As mentioned previously all of the interviews were emotive, but one in particular I found to be the most emotionally challenging and difficult to direct. Having spoken to the participant on the telephone to explain more about the study and to arrange the appointment, I had a sense of how angry he felt regarding the way his wife had been treated by professionals. When I arrived at the interview session he had several A4 sheets on which he had written a chronological account of his experience and he proceeded to read through this as soon as I started recording. Although we had been told that it was acceptable to refocus the participants to the research schedule, I felt that it was more important to let the participant tell his story as he wanted to, so I did not interrupt. At times during the telling of his story he became angry and upset, but I did not try and pacify him in any way as I felt it was what he needed to do. Once

he had recounted his story I asked him some of the questions from my interview schedule that I did not think had been covered in his statement and I included his data in my analysis. Allowing the participant to dictate the course of the interview in this way might have positioned me more towards being a clinician than a researcher and in terms of the overall study this perhaps detracted from my original goal. However, it seemed like ‘the right thing’ to do at the time and in retrospect I believe I would do the same again.

### **3.1.5 Data Analysis and Developing Themes**

The data analysis was the most challenging part of the whole research process for me. I had read papers and textbooks by people such as Jonathan Smith and Kathy Charmaz relating to carrying out qualitative research and had also attended lectures and seminars by various people, including Mike Osborne and Anna Madill. This reinforced the feeling that I had an understanding of the process for carrying out my analysis. In addition I was part of a qualitative support group set up within my training cohort to assist us to develop our skills and reflect on our research. When using IPA it is legitimate to analyse data as a whole once it has been collected and it is necessary for the researcher to immerse him or herself in the data so as to fully explore it.

When I attempted to do this, however, I found myself feeling overwhelmed by the quantity of data and I struggled to be able to make sense of what was being said. I found I was being very concrete in my coding and often ended up describing processes rather than interpreting them. This difficulty reflected my early experience of analysing example transcripts where I had a tendency be descriptive rather than interpretative. Both my academic and field research supervisors commented on how



concrete my initial draft analysis was and suggested that I had not got to the psychological meaning of what was being said. It was at this stage that my research supervision came into its own. I spent time with my field supervisor, who encouraged me to be more interpretative, and I redeveloped my themes several times, looking more at why things were said and what was meant rather than just reiterating what they had described.

### **3.1.6 Ensuring Quality and Legitimacy of the Findings**

IPA allows for the researcher to interpret the data based on what he or she considers to be important within the transcripts. This can open the process up to subjectivity and misinterpretation. Therefore it was important to have a means of checking that the interpretations I made were valid and could be traced back to the transcripts. To ensure this was the case, I shared interpretations with my academic and field supervisors, as well as using peer review via the qualitative support group. By sharing themes and showing the ‘paper-trail’ back to their origins in the transcripts I was able to validate my themes. It was interesting to note that people often interpreted the data differently and I am sure it would have been possible to have developed a whole different analysis depending on the researcher.

### **3.1.7 Reflecting on the Research Process and Supervision**

Reflecting on the research process has been identified as an important part of any qualitative study (Barker *et al.*, 2002) and this was another area where supervision and peer support were extremely valuable. I found elements of these to be useful in different ways when reflecting on the research process. For example, I often used my academic supervision to discuss issues of process, whilst my field supervisor

was more instrumental in helping me develop my ideas and analysis. The qualitative support group met once a month and these sessions were used for checking out the validity of interpretations amongst other things. However, it also operated more informally with Trainees sharing problems, ideas and experiences on a more ad hoc basis and this helped to clarify some of the more frequent issues that arose.

In addition I kept a research diary throughout the process. This detailed my own thoughts and feelings relating to the research process. In part it was to record things that happened contemporaneously so as to aid recall of events when reflecting back on the project. It also served the purpose of allowing me to voice concerns and doubts about my research. As previously stated there were occasions during the research process when I questioned my own ability to be able to complete the project and these were recorded in my diary. There were also times when things went well, for example following a good interview or when I recruited my extra participants through the second specialist service, and they were also entered. When it felt like the whole research process might be too much it helped to look back on these entries and reflect on what had been achieved.

### **3.1.8 The Personal Learning Process**

Stiles (1993) suggested that qualitative researchers were often drawn towards areas of personal interest. He further proposed that this would result in self examination by the researcher resulting in personal learning and change. In this instance my choice of research topic was guided by my own experience as a male carer. In addition, the project was influenced by a needs assessment I carried out of a 59 year-old man who had developed a WAD. This case had a significant impact on me and I discussed it at length with my supervisor of the time, although I did not fully

understand why it affected me so much. Through carrying out this research project I have been able to reflect on the processes I went through as a carer and to see the parallels between the difficulties I encountered and the difficulties I saw that couple facing. Similar practical problems and moral dilemmas were repeatedly spoken of by the participants in my study and this allowed me to contextualise my understanding of what I had gone through. I do not believe that one has to have lived through an experience to gain insight or understanding of it, but in this case I feel my experience allowed me a more intimate understanding of the situation.

Although I am generally confident in my own ability there were, as stated previously, occasions during the research process when I questioned my competency to complete a study at this level. This happened early on when I was struggling to recruit participants and the feeling was added to by the emotive nature of the participants' accounts. But rather than turning to my supervisors and support networks I internalised these difficulties and this compounded my self-doubt. I realised that I needed to address this, however, after attending a seminar on using IPA. It was emphasised how important the supervision process was to IPA as a methodology. This encouraged me to meet with my field supervisor and share some of my concerns and doubts. Following this I fully engaged in the supervision process during the rest of the project.

Carrying out this project also helped me to realise how difficult it is to conduct research alongside managing clinical commitments and maintaining a work/life balance. The competing demands of these areas highlighted why it is problematic for clinicians to engage in meaningful research projects. The whole process impacted on areas of my life I never expected it to and took far more of my time and resources than I considered it would. However, it also illustrated the importance of carrying out

research as a clinician. If we are to meet the needs of our client groups we must develop a thorough understanding of what those needs are and I believe that I now have a better understanding of the difficulties faced by the participants I interviewed. If I am in a position to conduct clinical research in the future I shall be mindful of these things and ensure that protected time is given over to the research.

### **3.1.9 Research Learning Outcomes**

Conducting this research project has developed my knowledge and skills in a number of ways. When I first considered my research study I felt that I would like to use a quantitative methodology as that was what I was most familiar with. However, once I had started to develop my research question it became clear that this project was better suited to a qualitative methodology and this also suited my clinical interest in working with people's narratives. I, therefore, had to develop my understanding of qualitative methodologies and decide which was best suited to my project. This built upon a range of existing skills such as selection of appropriate methodology, organising data collection, conducting interviews, analysing qualitative data and writing research reports. Many of these are transferable skills that I hope to utilise in clinical practice as well as in future research projects. In conclusion I would consider the whole process to have been a learning experience for me. I feel I have developed my clinical skills as well as my ability to conduct research and I think that I have gained confidence in my ability to conduct such research in the future.

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## **Appendix 1: Guidelines for submitting to the journal**

**Dementia: The International Journal of Social Research and Practice**

## Manuscript Submission Guidelines:

### Notes for Contributors

1. The aim of the journal is to publish original research or original contributions to the existing literature on social research and dementia. When submitting papers for consideration, please attach a letter confirming that all authors have agreed to the submission, and that the article is not currently being considered for publication by any other paper or electronic journal.
2. Each paper submitted, if considered suitable by the Editors, will be refereed by at least two anonymous referees, and the Editors may recommend revision and re-submission.
3. *Length of papers.* Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Please also supply an abstract of 100-150 words, and up to five keywords arranged in alphabetical order.
4. When submitting a paper for consideration, our preferred method of receipt is as an electronic version and as a Microsoft Word document. This should be sent via email attachment to one of the Editors outlined in Note 18, together with a separate covering letter. If this is not practicable, please supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations). Rejected papers will not be returned to authors.
5. Your typescript (written in English) needs to be typed using double spacing on one side only of white Aor US standard size paper, with generous left and right-hand margins (at least .cms) but without justification.
6. Your title page should give: one first name as well as the surname and any initials for each author; a maximum of four degrees/qualifications for each author and the current relevant appointment only; authors' accurate postal addresses; daytime telephone numbers, and fax and email numbers.
7. *Quotations.* Lengthy quotations (over 40 words) should be displayed and indented in the text.
8. American or UK spellings may be used. Please use single quotation marks. Dates should be in the form '9 May 2000'. Delete full stops/periods from 'USA' and other such abbreviations.
9. If the paper is accepted for publication, a copy of the final version will be required as either an email attached Microsoft Word document, or on disk in a PC-compatible format. The author is responsible for ensuring that the final version of the article matches exactly the one required by the Editors.
10. *Tables.* You should present tables in your manuscript typed double-spaced on separate sheets and containing only horizontal rules. Each table needs a short



descriptive title above it. Column headings should clearly define the data presented. If necessary, suitably identified footnotes should be included below. Take care to include all the units of measurement. The table needs to be cited in the text.

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

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

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

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

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

Morse, J. M. (1994). Emerging from the data: The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.),

*Critical issues in qualitative research methods* (pp. 23-43). London: Sage.

*Multi-authored articles*: in the text, when the work has two authors, always cite both names every time. When there are more than two authors and less than six, cite all authors the first time and after that, just the surname of the first author and et al. The names of all authors should be given in the reference list.

14. *Language and terminology*. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

15. *Abbreviations*. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

16. The corresponding author will receive page proofs for checking. Twenty-five free offprints will be sent to the corresponding author, and each of the co-authors will receive a free copy of the journal.

17. *Copyright.* On acceptance of their paper, authors will be asked to assign copyright to SAGE Ltd, subject to retaining their right to reuse the material in other publications written or edited by themselves, and preferably due to be published at least a year after initial publication in the journal. Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere.

18. *Typescripts.* Authors should retain a copy of their typescript and send an identical electronic version as a Microsoft Word document, together with all figures and tables and a separate covering letter, via email attachment to:

*For USA and Canadian contributors:*

**Phyllis Braudy Harris**

Editor, *Dementia*:

The International Journal of Social Research and Practice,

Department of Sociology,

John Carroll University,

North Park Boulevard,

University Heights,

Cleveland, Ohio, USA.

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Alternatively, authors should retain one copy of their typescript and supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations) and a separate covering letter, to one of the Editors named above.

19. *Reviews*. Books for review should be sent to:

Book Review Editor - Dementia

**Heather Wilkinson**

College of Humanities & Social Science,

Univeristy of Edinburgh,

55-56 George Square,

Edinburgh

EH8 9JU, UK.

[email: hwilkins@staffmail.ed.ac.uk]

20. *Innovative Practice*. The Journal also welcomes submitted papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal can be between 750-1500 words and should follow the criteria set out above. Correspondence should be sent to:

**Jo Moriarty,**

c/o School Offices,

School of Social Science and Public Policy,

Strand Building,

King's College London,

London, UK.

[email: jo.moriarty@kcl.ac.uk]

## **Appendix 2: Participant Information Sheet**

**Information Sheet.**

You are being invited to take part in a research study. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read the following information carefully. You may want to discuss the study with your wife/partner or some other person before deciding to take part.

Part 1 of this form tells you the purpose of the study and what will happen to you if you agree to take part. Part 2 gives more information about the conduct of the study. Please ask if there is anything that is not clear or if you would like more information.

This research study will be carried out in partial fulfilment of the degree of Doctorate of Clinical Psychology, from the University of Leicester. The study itself will involve the interviewing of 8-12 male carers of wives/partners with a dementia which is acquired before the age of 65 (known as a Working Age Dementia or WAD). The interviews will consist of a series of open questions which look to explore the individual experiences of carers and how they have been affected by their caring role. These interviews will be tape recorded. Once the interview data is transcribed it will be read through by the researcher who will identify what appear to be the key themes and issues that are raised within the interviews. The researcher will then compare these against the other interviews to look for common themes and differences. This is known as qualitative data analysis.

Please feel free to ask if there is anything that is not clear or if you require further information.

**Part 1****Study title.**

A Qualitative Study of the Way in Which Male Carers of Spouses with Working Age Onset Dementia Experience and Perceive Their Caring Role.

**Purpose of the study.**

The study aims to identify the key experiences of male carers of spouses who have developed a WAD. There is little existing research in this area and, at present, services to this group (and WAD services generally) vary greatly depending on location. In helping to identify the issues that are important to carers this research might help to inform future service provision.

**Why have you been invited to take part?**

You have been invited to take part in this study because you have been identified as being a caregiver to your wife/partner. Taking part in the research is entirely voluntary and will not in any way affect the care your wife/partner receives or any services you use. You can withdraw from this study at any time in which case all data relating to your part in the research will be destroyed.

**Will taking part in the study be kept confidential?**

Your GP will be notified that you have consented to take part in the study, but your interview will be kept completely confidential.

Apart from the lead researcher, Steve Grant, the only other person who will have access to your interview prior to identifying information being removed will be the transcriber. They will be recruited through the University of Leicester and will sign a confidentiality agreement stating that they will not copy or share any of the information included in the transcript.

**What will taking part involve?**

The research consists of you being interviewed by Steve Grant, the lead researcher, at a place convenient to you. The interview will last for between 30 minutes and 1 hour and you will be asked a series of questions regarding your experience of caring for your wife/partner following her diagnosis of dementia. The interviews will be tape recorded and later transcribed by the professional transcriber. The completed thesis may contain direct quotes from your interview, but all identifying information will have been removed.

All source materials (either taped or written) will be stored confidentially at the University of Leicester and destroyed after a suitable period.

### **What are the disadvantages of taking part?**

There are no disadvantages of taking part as far as we can see. However, some people may feel that thinking about some of the issues raised during the interview might generate some anxiety. If you feel that you would like to speak to someone about this, you can contact either Steve Grant, the lead researcher, or Dr David Connelly, the Clinical psychologist supervising the research. Their contact information is printed below.

### **What are the benefits of taking part?**

Taking part will mean we may find out more about how men take care of their wives/partners when they have dementia. This means that the NHS might be able to provide more suitable support for men in this position. The results will be fed back to all of the consultants' teams and service providers collaborating in this research. The findings may also be published in professional and academic journals.

## **Part 2**

### **Who is funding the study?**

The research has been funded by the University of Leicester.

### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a research ethics committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the Derbyshire Research Ethics Committee.

### **Who should I contact if I want to find out more or want to make a complaint?**

The lead researcher for this project is Steve Grant. You can contact him about any aspect of this research. The research is jointly supervised by Professor Mike Wang of the University of Leicester and Dr David Connelly (Clinical Psychologist) at the Sheila Gibson Unit, Nottingham Healthcare NHS Trust. If you have any queries about the research but do not wish to contact Steve Grant, you can contact either Professor Wang or Dr Connelly.

Contact Information:		
Steve Grant Clinical Psychology Department University of Leicester 104 Regent Road Leicester LE1 7LT Tel: 0116 223 1639 E mail: sdg12@le.ac.uk	Dr. David Connelly Clinical Psychologist Sheila Gibson Unit Chilwell Lane, Bramwell Nottingham NG9 3DU Tel: 0115 907 6127 E mail:david.connelly@nottshc.nhs.uk	Professor Mike Wang Clinical Psychology Department University of Leicester 104 Regent Road Leicester LE1 7LT Tel: 0116 223 1639 E mail: mw125@le.ac.uk

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Contact Information of the person who gave you this information:

[illegible]

Participant Information Sheet- Version 2.0 (July 2007)

### **Appendix 3: Research ethics approval letters**





RE: PC\_ethics2006 - steve grant  
Colman, Prof A.M. [amc@leicester.ac.uk]

Sent: Wednesday, June 13, 2007 11:42 AM  
To: [sdg12@leicester.ac.uk](mailto:sdg12@leicester.ac.uk)

Dear Steve

Your project (A qualitative study of the way in which male carers of spouses with working age onset dementia experience and perceive their caring role) has been approved by the Psychology Research Ethics Committee.

This e-mail is the official document of ethical approval and should be printed out and kept for your records or attached to the research report if required - this includes all undergraduate and postgraduate research.

We wish you every success with your study.

Andrew M. Colman  
Psychology Research Ethics Committee Chair

-----Original Message-----

From: www-data [<mailto:webserver-admin@leicester.ac.uk>]  
Sent: 12 June 2007 15:57  
To: amc@leicester.ac.uk  
Subject: PC\_ethics2006 - steve grant

Proposer: PC\_ethics2006 - steve grant  
email: [sdg12@le.ac.uk](mailto:sdg12@le.ac.uk)  
status: DclinPsy year 2 student  
supervisor: Professor Mike wang  
title: A qualitative study of the way in which male carers of spouses with working age onset dementia experience and perceive their caring role.  
date: 12/06/07  
preapproval: LMRC  
describe:  
tellvoluntary:  
obtainwrittenconsent:  
observe:  
maywithdraw:  
allowomit:  
tellconfidential:  
debrief:

-----  
mislead:  
distress:  
animals:  
kids:  
sen:  
patients:  
custody:  
criminals:

-----  
route:

-----  
routeAdesc:

-----  
routeBdesc:  
RouteBsupp:

## **Appendix 4: Interview Schedule**

### Interview Schedule

- Introduction to the interview consisting of; confidentiality statement, reminder of the participant's right to withdraw/withdraw data, checking that the Participant Information Sheet has been read and understood, and ensuring that the consent form has been signed.
- Brief reminder of the purpose of the study.
- Begin Interview

Name of carer/occupation.....

Name of spouse/relationship.....

Present age of carer.....

Present age of spouse.....

Diagnosis/ Length of time since given.....

Number of children.....

Ethnicity.....

### Interview Questions

1. Can you talk me through what it was like when...received her diagnosis?
  - a. how was the diagnosis given?
  - b. What were your immediate hopes and fear?
2. In the time since the diagnosis have your initial feelings been realised?
  - a. If so, in what way?
  - b. If not what has been different or unexpected?
3. Now that you have lived with this for some time do you feel that your role as a husband/partner has changed?
  - a. How is it different/is there anything that feels the same as before?
  - b. can you tell me how you have found being a carer?

- c. can you tell me about how you are supported?
- 5. How do you see the future?
  - a. What are you feeling positive about/what are your concerns?
- 6. Do you feel that you have gained from the experience of becoming a carer?
  - a. In what way?
- 7. Is there anything about the experience of being a carer that is really important to you that you would like to tell me about?
- 8. Is there anything about the interview today that you would like to reflect on?

Interview Schedule- Version 1 (May 2007).

## **Appendix 5: Participant Consent Form**



**CONSENT FORM**

**A Research Project to Explore Your Experience of Caring for a Spouse with Working Age Onset Dementia.**

I have read the Information Sheet about this project

☐

I have met with Steve Grant, who has explained the project to me.

I have had the opportunity to ask questions. I understand what I will be required to do.

☐

I understand that the interview will be tape recorded. I understand that the data will be kept in a safe and secure place and the information I give will be used for this project only.

☐

I understand that the interview will be transcribed by a person other than the Steve Grant and that this person will have agreed to keep all details confidential.

☐

I understand that the information I give will be confidential, unless the researcher becomes concerned someone is at risk.

☐

I understand that I can change my mind and withdraw from the project at any time. If I do, any information I have given will be withdrawn from the project.

☐

I agree to the use of fully anonymised direct quotations from the interview being used in the study report.

☐

I understand that sections of any of my research records where appropriate may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

☐

**I AGREE TO TAKE PART IN THIS PROJECT**

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



I confirm I have explained the nature of this study, as detailed in the Information Sheet, in terms which, in my judgement, the participant has understood.



\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Consent Form- Version 2.0 (July 2007)

## **Appendix 6: Transcriber Confidentiality Agreement**

**Confidentiality agreement  
Transcription of research interview tapes for Steve Grant**

I agree keep the information I am transcribing from the tapes strictly confidential.

I will not discuss the contents of the tapes with anyone other than Steve Grant

If I believe I recognize the person on the tape I will cease immediately and tell Steve Grant that I cannot continue with the particular tape.

I will not make copies of any of the tapes.

I will keep the tapes safely.

Nobody else will be allowed access to the tapes during the transcription process.

Signed:

Name:

Date:

Countersigned by:

Date: