Declaration:

I, Peter John Brown certify that this work:

Care Giving Experiences of Older Husbands

Providing Care for Wives with Dementia

Is original and has not been submitted for a higher degree at another institution.

Peter Brown

Signed: ________________________________________________
Abstract

As there were few studies of older husbands’ experiences associated with providing care at home for spouses with dementia, the researcher designed a two-stage study to examine their experiences. In stage one, a qualitative paradigm guided one-to-one interviews with sixteen care giver husbands to examine their care giving experiences. Analysis of the interview data guided the identification of four models of care giving related to the past, present, future and an overall model over time. To verify findings in stage one, Chapter Five of the study was sent out to five other older husbands, who were providing care, to comment on the findings. From their comments, the writer felt that there was general agreement that the researcher’s interpretations of the data and derived models reflected husbands’ experiences accurately. In stage two, a comprehensive questionnaire was developed and questionnaire items were identified from multiple sources. In stage two the researcher utilized a quantitative approach to investigate husbands’ experiences. A representative sample of 71 care giver husbands participated by completing the questionnaire and standardized measures of burden and depression along with other measures of husbands’ characteristics and experiences and level of wives’ illness and associated behaviours. The resulting data were analysed using correlational analysis to examine the relationship between the independent variables (questionnaire items, selected standardised measures) and measures of husbands’ burden and depression (dependent variables). Predictive models of care giver burden were care giving seen as a ‘job’, effects of care giving on the husband-wife relationship, and use of avoidant-evasive coping strategies by husbands. The best predictive models of care giver depression were use of avoidant-evasive coping strategies and changes in husbands’ emotional health status related to care giving.
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CHAPTER ONE

INTRODUCTION

This chapter describes the reasons why this particular topic was chosen by the researcher and its relevance to husbands who were caring at home for their wives who had been diagnosed with dementia. It also provides a description of each of the chapters that follow.

Introduction

This chapter highlights how the researcher became interested in the experiences of older husbands who were providing care for wives with dementia at home. Recent health, demographic and social changes that have taken place in Australian society and families account for an increasing number of males becoming involved in care giving. The specific objectives of the study are described and outlines of the chapters that follow are set out. Reasons for interest in the topic were threefold: (1) the increasing impact on care givers of dementia burden, (2) discussions with U.S. researchers who were studying care givers’ experiences associated with providing care for family members with dementia, and (3) a personal experience of a family member with dementia and professional experiences with patients and clients with dementia.

1 This thesis uses ‘care giver and carer interchangeably
1.1 Dementia: Significance of the Problem

The worldwide number of persons with dementia in 2005 was estimated to be 24 million persons (Alzheimer’s Disease International, 2006). In 2003, almost half (46%) of the people with dementia lived in Asia, 30% in Europe, 18% in North America, and 52% lived in less developed countries (Wimo, Winblad, Aguero-Torres & von Strauss, 2003). In the U.S., the Alzheimer’s Association has reported that in 2007 there were more than 5 million people living with Alzheimer’s disease. This number includes 4.9 million people over the age of 65 and between 200,000 and 500,000 people under age 65 with early onset Alzheimer’s disease and other dementias. This is reportedly a 10 percent increase from the previous prevalence nationwide estimated rates of 4.5 million (http://www.alz.org/news_and_events_rates.asp). Currently, dementia is one of the most significant health problems facing Australia and will become an even bigger problem. In 1995, when Australia had a population of 18 million, there were estimated to be 130,000 people with dementia and in 2041, the number of people with dementia is projected to be between 420,000 and 730,000 with a population of 25 million people (Jorm, 2001; Access Economics, 2005). This phenomenon is associated with increasing numbers of people living into old-old age when prevalence rates for dementia will be as much as 24% in the 85-89 age group, 34% in the 90-94 age group, and 45% in those aged 95 and over (Wimo et al., 2003). According to the Australian Institute of Health and Welfare (AIHW, 2004) the incidence of dementia doubles for every five year cohort after age 65.
Dementia, and Alzheimer’s disease in particular, is one of the main disabling conditions for those 65 and over (AIHW, 2000a.) and dementia is projected to be the number one source of disease burden (a concept explained in Chapter Two) in 2016 in Australia for women, and the fifth for men. In Australia, financial costs for society and carers associated with dementia, is estimated to be $6.6 billion each year (Rees, 2003).

Dementia is a syndrome that is acquired, progressive and causes global impairment of higher brain function. These changes interfere with the sufferers’ ability to carry out their activities of daily living (Coni, Nicholl, Webster & Wilson, 2003). According to prominent British psychogeriatricians and authors, Jacoby and Oppenheimer (2002), causes of dementia are numerous but the most common are Alzheimer’s disease and Vascular dementia.

Signs and symptoms of dementia vary from individual to individual but commonly memory is affected first. Changes also occur in the person’s orientation to their environment, thinking, comprehension, language, learning capacity, calculation and judgment (American Psychiatric Association, 2002). People with dementia may also experience delusions, hallucinations and depression (Robinson, Adkisson & Weinrich, 2001). They might wander aimlessly, pace, scream for no apparent reason, bite others, fidget incessantly and appear extremely agitated (Thomas & O’Brien, 2004).
Dementia causes significant disabilities for the person experiencing it. According to AIHW (2000a.) in 1998 there were 3.6 million people in Australia who had a disability. The rate of disability increases with age, with people aged 85 and over having the highest rate. Significantly, 94% of people with dementia experience a disability causing profound restrictions compared with 19.3% of all other disabled Australians (Access Economics, 2005). Disabilities often result in the need for formal care provision, for example, the older person with dementia may be placed in a high care facility such as a nursing home, or commonly a family member, a wife or adult daughter, may have to take on the role of carer.

1.2 Family Carers of People with Dementia: Who are they?

Spouses (wives in particular) and adult daughters have been the main source of help for people with dementia (Leong, Madjar & Fiveash, 2001; Mittelman, 2003). Adult children carers of people with dementia have been found to have a mean age in their 50’s and spouse carers of people with dementia a mean age of late 60’s and early 70’s (Australian Bureau of Statistics [ABS], 2002). Most carers provide care for the person in the same household. More recently, there has been an increasing tendency for males to provide care at home for family members with dementia (AIHW, 2000b.).

According to Houde (2001), male care givers provide an important source of informal care for functionally impaired older adults with dementia in the
community. This assertion is validated by the fact that when carers’ studies were examined (for example, Mays, Holden & Lund, 1999; Kramer & Thompson, 2005), male participants varied between 28% and 33% of samples numbers. Australian researchers, Cox & Spalding (1995), have stated that male carers are most likely to be older husbands who are providing care for their wives. A review of thirty-seven carers’ studies undertaken by the writer indicated that there were few studies of older husbands’ experiences who were providing care for wives at home who had been diagnosed with dementia and none in an Australian context. In particular, the researcher was interested in the phenomena of care giver burden and depression in an Australian context. This thesis begins to fill this needed knowledge gap.

1.3 Personal and Professional Interest in the Topic

The writer’s interest in the topic arose out of professional exposure to carers’ experiences in a variety of service settings, a personal experience, and a study tour to the U.S., visiting the University of Utah Centre for Gerontology. Staff of the Centre shared findings from their dementia carers’ research studies and the writer was encouraged to study carers’ experiences in an Australian context and to share findings with them. Since this visit the writer has conducted several such studies in New South Wales and other states of Australia.

Interest also arose from the writer’s experiences as a nurse for many years
working with older people in a variety of service settings, including hospitals, 
 nursing homes, hostels, and in the community, and his involvement on a personal 
 level providing supportive care for his own mother who developed Alzheimer’s 
 disease but who has since died as a result of this disease.

1.4 Purpose of the Present Study

The purpose of the present study was to provide a description of older husbands’ 
 care giving experiences as little was known about their experiences in an 
 Australian context and the nature and degree of any negative consequences for 
 them.

1.5 Rationale for the Study

As the Australian population is ageing, the number of older people with dementia 
 will continue to multiply and increasingly family members will be called upon to 
 provide care at home (Alzheimer’s Australia, 2003). Although, as already 
 highlighted, caring has been primarily provided by wives and adult daughters, 
 there is increasing evidence to suggest that a larger number of husbands are taking 
 on the carer role (Houde, 2001). Their numbers are estimated to be between 33% 
 and 44% of family carers and most of these are husbands (Neufeld & Harrison, 
 1998; Coe & Neufeld, 1999; AIHW (2000b.). This phenomenon is related to 
 significant demographic and social changes in the Australian and other western
populations, which are noted here and will be described further in the following chapter. Changes include:

1. an increase in the number of males, and older men in particular, who are able to provide care (Mays et al., 1999; Houde, 2002; Kramer & Thompson, 2005);
2. increased numbers of older women with dementia for whom care is required (Jorm, 2001; Access Economics, 2005);
3. broadening of gender roles (Houde, 2001); and
4. decrease in the number of adult females who can provide care for family members with dementia (Houde, 2001; Gallichio, Siddiqi, Langenberg & Baumgarten, 2002).

Health professionals, including nurses, need to be aware of these demographic and social changes and their implications for health service provision as these workers will be required to assist older males in relation to their care giving role and it might be found that they have different needs to those of older wives and daughter carers. An important consideration is the need to identify male carers ‘at risk’ of developing physical and emotional problems related to care giving so as to provide appropriate physical, emotional, educational support and information about appropriate services.

1.6 Specific Objectives of the Study

The main objectives of this study were to 1) explore the meaning of care giving
from the older husband’s perspective; 2) investigate husbands’ understanding of their wives’ illness; 3) identify husbands’ perceptions of their own present issues and problems; 4) explore their reactions to the care giving role; 5) examine husband-carers’ perceptions of the support provided to them by formal and informal carers; and (6) determine husbands’ needs related to care giving that remained unmet.

1.7 Chapter Outlines

The chapters of this thesis provide an overview of the study including the research process that was followed, a review of the literature related to the topic, the theoretical perspectives employed and methodologies utilised, the study findings in relation to husbands' care giving experiences, discussion of findings, conclusions to the study and recommendations for further research.

Chapter Two focuses on the clinical, demographic and social aspects of dementia through a critical review of the literature, providing an overview of the syndrome of dementia and concepts of carers, care giving, burden and depression related to care giving. Specifically, it provides definitions of dementia, describes the various types and stages of dementia, and identifies problem behaviours associated with dementia. Its prevalence and incidence and the number of people with dementia living in the community are highlighted. It proposes that in the past and in the main, care giving has been the responsibility of wives and adult
daughters. However, it points out that males, for various socio-demographic reasons, have begun to assume more responsibility for care giving. There was some evidence noted that a few male carers found the role to be emotionally satisfying, however, most found it to result in negative consequences for them.

The literature of specific relevance to this study of carers, and of older male spouse carers in particular, is reviewed and examined in Chapter Three. Some studies had examined the experiences of family carers generally without examining whether or not there were any differences in the experiences of male and female carers. Others were designed to compare the differences between male and female carers’ experiences. There were eleven studies that had focussed on the experiences of male carers in relation to care giving. A few studies utilised a qualitative research design, while others employed a quantitative design. Several studies employed a mixed method approach to studying carers’ experiences, for example, focus groups and standardised measures of carers’ burden levels. It was clear from the literature review that many carers, both male and female, experienced emotional and physical consequences related to providing care. However, only three of the eleven male carer focussed studies had examined older husband carers’ experiences associated with providing care at home for wives with dementia and little had been discovered about their experiences from these studies. Moreover, there were no studies that had been carried out in an Australian context. None of the three research studies had employed a ‘staged’ approach to a study of male carers’ experiences and this will
be described under a description of Chapter Four.

Chapter Four discusses the theory and methods used to investigate the research topic. In stage one, the researcher utilised a grounded theory methodology informed by a symbolic interactionist perspective to examine the experiences of sixteen older husbands who were providing care for wives at home who had a dementing illness. From the information derived, further reflections on the existing literature and discussions with service providers, carers and the researcher’s supervisor, the researcher developed a comprehensive questionnaire to be administered in stage two to a larger number of male carers. In addition, several standardised measures were employed to examine various concepts that were highlighted from stage one interviews, for example, many males indicated that they were experiencing a sense of burden, therefore, the researcher identified and utilised an appropriate standardised measure of burden that the researcher had used in earlier studies of carers’ burden. One of the challenges that arose in stage two was related to the number of carers (n=71) compared to the number of variables (see Appendix Three) that the researcher was interested in examining. To overcome this problem, the researcher organised the questionnaire items (independent variables) into eight clusters comprising between four and eight variables and the combined and separate contributions of the cluster variables to the variation of each of the dependent variables (for each of which a single group score was statistically derived), was examined using multiple regression analysis.
Chapters Five, Six and Seven describe the findings based on analysis of the data from each stage. In Chapter Five, findings from stage one interviews are described and discussed. From the data four models of older husbands’ care giving experiences were developed. The first three models related to their past, present and future experiences, and a fourth, overall model of male care giving, was also developed. Model one highlighted the central notion of husbands’ care giving as being their commitment to provide care based on their marriage vows and sense of responsibility even in the face of their own distress. Model two reflected husbands’ present care giving experiences (at the time of interview) and highlighted that husbands’ sense of burden resulted from a state of tension created by the effects of care giving demands and increasing need for supervision on the one hand, and their ability to meet their own basic needs on the other. In model three it was clear that as husbands contemplated the future they were feeling discouraged because of their perceptions of how the disease would progress and doubts about their own ability to manage. Model four integrates the main themes from each of the other three models.

In Chapter Six a descriptive analysis of the cluster variables used in stage two of the study is provided. Over 50 per cent of husbands were in receipt of the Age or other Pension as their main source of income. Most were providing care on a continuous basis and for many hours during each day. Interestingly, many husbands described their care giving role as if they were ‘doing a job’ and a high proportion emphasised the need to be efficient in order to cope with the role.
There is evidence presented in the chapter that suggests that care giving was taking a toll on the relationship with their wives. For some, lack of consistent and continuing support from other family members made husbands feel isolated and unsupported. Whilst carer groups offered support for those who attended them, their experiences at the groups were not always positive. The chapter will also identify unmet service needs as identified by husbands, specifically for respite care, time out to attend to their own health and fitness, and the need for others’ company and support.

Chapter Seven examines husbands’ experiences of burden and depression in relation to care giving further. Standardised measures of burden and depression were utilised to confirm or disconfirm findings in the earlier studies that husbands were experiencing a sense of burden and depression. Several other measures were employed to provide more information about the variables that might have been impacting on their experiences of burden and depression. From the analysis, three predictive models of burden were identified and included care giving perceived as a job, effects of care giving on relationship, and avoidant-evasive coping strategies. In relation to depression, there were four predictive models. These were avoidant-evasive coping strategies, change in emotional health status, affective personality traits, and ease of contact with relatives and friends.

Chapter Eight presents the conclusions and discussion of study findings in relation to the research questions, limitations of the stages of the study are identified, and
further areas of research are suggested. The application of findings for nurses working with older carers is also highlighted.

1.8 Conclusion: The Link with Nursing Practice and Theory

The purpose of the study was to explore the experiences of older husbands who were providing care at home for wives who had been diagnosed with dementia. Although each husband’s experience was unique there were experiences common to all carers in this situation. The study should add to nurses' and other health professionals’ knowledge of husbands’ care giving experiences and contribute new understandings to the existing body of knowledge in this area. Information about husbands’ interactions with others, for example, nurses in their professional care giving roles, will assist them to identify those husbands who may be ‘at risk’ so that appropriate emotional, physical and educational support is provided, or so that they might refer them to other services and service providers.
CHAPTER TWO

DEMENTIA AND CAREGIVERS

Clinical, Demographic and Social Aspects of Dementia:

Critical Review of the Relevant Literature

This chapter examines the syndrome of dementia, including definitions, prevalence, types, stages, associated problem behaviours and their management. Family care givers provide care for almost fifty percent of people with dementia in the community with varying levels of formal and informal assistance. Male carers comprise up to 33% of carers in some studies. Little was known about their experiences of care giving.

Introduction

The focus of this study is the experiences of older husbands who were providing care at home for wives who had been diagnosed as having dementia. This focus is a relatively unexplored area. At the time the study commenced, and as noted in the previous chapter, there were few overseas studies that had given attention to this issue and no studies in an Australian context had then been published. To provide a background to the phenomenon of interest this chapter will examine the syndrome of dementia, outlining the nature of the illness, its incidence and the difficulties it creates for family carers. It will also examine the generic concept of care giving.
Observably, most home-based care for ailing family members is provided by adult daughters or wives although there is an increasing trend for males and in particular husbands, to care at home for wives who have developed dementia (Houde, 2002). This trend, as identified in Chapter One, is related to several demographic trends including an increase in the number of older men (ABS, 1999) and their availability to provide care especially if they have retired; an increase in the number of older females with dementia for whom care is required (Access Economics, 2005); a broadening of gender roles resulting from challenges to the traditional role of men in western societies as breadwinner and protector (Houde, 2001; Flood, 2004), and a reduction in the number of younger adult females (mainly daughters) (Houde, 2001) who are able to provide full-time care due to their trend to return to the workforce in a full, part-time or casual capacity or to study, once their own children have grown up and left home (Gallicchio et al., 2002; Houde, 2002).

Other concepts examined in the literature review and reported in this chapter are family carers, both male and female, and their experiences of burden and depression although carers’ experiences will be examined more fully in the literature review (Chapter Three). Before examining these experiences, this chapter will provide a critical review of the syndrome of dementia which was affecting wives who were being cared for. In particular, it provides a discussion of the nature, types, causal mechanisms, incidence and prevalence, characteristics and treatment of dementia.
2.1 Syndrome of Dementia

Dementia is a syndrome or set of symptoms and signs which usually occur together (Elder, Evans & Nizette, 2005) and is due to a disease in the brain. It is usually of a progressive or chronic nature, in which there is impairment of memory, thinking, orientation, learning capacity, language and judgement. These changes to cognition occur in a fully alert person and this feature distinguishes dementia from delirium in which there is an alteration of consciousness (American Psychiatric Association, 2002; Fick, Agostini & Inouye, 2002). Changes in cognition in dementia are commonly accompanied, and occasionally preceded by deterioration in emotional control, social behaviour or motivation. Burns & Hope (2004) state that the cognitive decline that occurs in dementia, regardless of the underlying cause, represents a decline from the individual’s earlier functioning and is sustained, although fluctuating and progressive over time.

Signs and symptoms of dementia vary and this is not only due to individual differences but is also related to the specific type of dementia, the personality of the person experiencing the dementia, the presence of other problems (physical or psychiatric), and the environment, for example, at home, or in a nursing home context, in which the dementia is being experienced (Jacob & Oppenheimer, 2004). As noted earlier, dementia affects the individual’s cognition, behaviour, physical status and emotions. These changes often impinge significantly on
relationships with others (Edwards, 2003; AIHW, 2004; Smith & Buckwalter, 2005).

Cognitive Signs and Symptoms of Dementia

Memory is often the first functional behaviour to be affected in dementia and deterioration in short term or recent memory, in particular, causes the most difficulty. Long-term memory is not affected to the same extent until quite late in the disease (Kingsley, 2000; Mace & Rabins, 2001). Changes may also affect the person’s orientation (to time, place and person), thinking (which becomes more concrete), comprehension, language, learning capacity, calculation and judgment (Edwards, 2003; World Health Organisation [WHO], 2003). Changes in these behaviours will severely affect daily activities, interactions, and overall functioning. Other cognitive changes include apraxia, agnosia, and aphasia. Apraxia is the “inability to perform certain movements on command or imitation” (Ratnaike, 2002, p.189) and includes a loss of coordination thus affecting the person’s mobility and daily activities of living such as dressing and eating. In agnosia the person fails to recognise or identify objects and their purpose due to sensory function changes, for example, where an older male with dementia tries to cut up his food using a fork. Aphasia relates to deterioration and disturbance of language, for example, the person with dementia may be unable to comprehend what is being asked of them and is therefore unable to respond accordingly (Ebersole, Hess, Touhy & Jett, 2005).
Behaviour Changes Associated with Dementia

Behaviour changes associated with dementia have been variously referred to as inappropriate (Brodaty, Draper & Low, 2003), for example, an old man exposing himself in company; challenging, that is, the changes create difficulties for the carer (Brodaty et al., 2003; Lai & Arthur, 2003), for example, waking during the night and turning on the gas stove without lighting it; or problem behaviours (includes paranoid and delusional ideation, hallucinations) (Robinson et al., 2001).

For the purpose of this study the writer will use the term challenging behaviours as this refers to behaviours, associated with dementia, that cause difficulties for others. It is judged from the observer’s point of view (often the family carer or nurse) as being challenging whilst the older person who is experiencing the behaviour may consider the behaviour as being appropriate (or even goal-directed, for example, trying to leave the marital home to return to the original family home) (Smith & Buckwalter, 2005).

Challenging behaviours include aimless wandering, pacing, cursing, screaming, biting, and fighting. Agitation is a common problem that people with dementia experience. It has been defined as “an inner tension associated with excessive motor activity” (Thomas & O’Brien, 2004, p.517) which disturbs others. It may follow aggression or abuse, be performed to excess, for example, in the form of
repetitive mannerisms or questions, or may be inappropriate for the social situation, for example, taking clothes off in public.

Psychotic symptoms, for example, delusions and hallucinations, occur in 20% to 50% of cases of dementia (Mayeux & Sano, 1999; Tarrier, Barrowclough, Ward, Donaldson, Burns & Gregg, 2002). Common delusions in patients with Alzheimer’s disease include the belief that people are stealing their possessions and misidentification, for example, the person might state that her husband is a stranger. Devanand, Jacobs, Tang, Del Castillo-Castaneda, Sano, Marder, Bell, Bylsma, Brandt, Albert & Stern (1997) have noted moderate associations among paranoid delusions, mis-identification delusions and behavioural disturbance. Hallucinations are perceptions that occur in the absence of an external stimulus and affect all the senses (Townsend, 2003). They are more common in severe dementia and more likely to be visual, for example, they might see their children when there is no one else present, than auditory, for example, where the person hears one of their children speaking to them when there is no one else present (Devanand et al., 1997). Also, with the progression of Alzheimers disease, there is a steady increase in the percentage of time spent awake (Mayeux & Sano, 1999; Hecker, 2002) which may suggest changes are occurring in the sleep-wake cycle.

As there are just on approximately half of the people with moderate or severe dementia who still live in the community with a family carer, it may be predicted that family carers might be the recipients of some of the behaviours described.
Family members, therefore, who are providing care in the home may be faced with managing a range of challenging behaviours during their carer role (Hope, Keene, Fairburn, Jacoby & McShane, 1999). Challenging behaviours may make placement, when it becomes necessary, difficult to achieve and where placement occurs the behaviours may make management difficult for the formal carers (Gaugler, Kane, Kane & Newcomer, 2005), for example, nursing staff. Challenging behaviours may be severe, unpredictable and frequent. It should be pointed out though, that there is not always a fixed relationship between behavioural changes and cognitive decline in Alzheimer’s disease and they can occur at all stages of Alzheimer’s disease (Mace & Rabins, 2001). A stage theory of dementia is outlined shortly in this chapter.

**Physical Signs and Symptoms of Dementia**

Changes in memory, inability to coordinate activities, poor judgment and an inability to learn new skills, all affect the ability of the older person with dementia to carry out the physical demands of daily living. Generally, there is a pattern of decline that occurs beginning with Instrumental Activities of Daily Living (IADLs), progressing to Activities of Daily Living (ADLs) (Matthews, Tabolt, Dunbar-Jacob, Sereika, Schulz & McDowell, 2004) and during the end stage of dementia even the skills associated with eating and speaking may be lost. Loss of mobility may cause persons with dementia to be unsteady, at risk of falls or other injury related to unstable gait, and eventually to become chair- or bedbound.
Diminished motivation and, therefore, physical activity will in turn lead to reduced muscle strength. Incontinence (urinary and bowel) often occurs in end stage dementia (Mace & Rabins, 2001).

Changes in Personality and Emotional Signs and Symptoms of Dementia

According to Dicker (2001), behavioural and emotional symptoms of dementia have been identified in several studies as the single greatest cause of care giving stress. The person with dementia may experience changes in emotions and personality. Changes in personality may even be noticed in early stage dementia with the person becoming, for example, less spontaneously responsive to others. Alternatively, existing personality characteristics may become more pronounced (Gaugler et al., 2005). In end stage dementia many carers describe the care recipient’s original personality as ‘no longer being there’. Loss of emotional control often accompanies or precedes cognitive impairment associated with dementia (WHO, 2003). Mood changes in dementia can include depression, anxiety, irritability, agitation, restlessness, apathy and suspicion (Mace & Rabins, 2001). Griffith & Arnold (2005) report that such emotional changes associated with dementia have been well described in various studies.

One system which usefully describes the changes in behaviour associated with the level or stage of severity of dementia is the Clinical Dementia Rating Scale (CDRS) developed by Berg (1988). The CDRS was used in stage two of this
study and is described in Chapter Four. It describes dementia as occurring in three stages. This will be described in the next section.

2. 1. 1 Stages of Dementia

In the first stage, moderate memory loss (short term and for recent events), difficulty in orienting for time or place, moderate problem solving difficulties are more evident, whilst personal care may be unaffected. In Stage Two, severe memory loss is more pronounced although memory for past events may still be present and memory for new material rapidly lost. Disorientation to time and place is more pronounced and severe impairment in handling problems and judgment in social situations are often prominent features. Hobbies and interests are very restricted and poorly sustained with only the ability to carry out very basic tasks being retained. Personal care activities will require prompting and supervision. Stage Three is characterised by severe memory loss and disorientation to time and place, inability to make judgments or problem solve, and severe deterioration in the ability to carry out home chores or hobbies and personal care will require substantial help.

Although it is sometimes useful to describe dementia as occurring in stages, from the writer’s personal and professional experience, individual sufferers do not always fit neatly into a particular stage and hypotheses that a three stage model of dementia may be an over simplification of what is in fact a complex
phenomenon. Sometimes, for example, it is not always clear where one stage ends and another begins.

2. 1. 2 Accurate Assessment is Essential

As other conditions may be mistaken for dementia, the importance of accurate assessment cannot be stressed too strongly (American Psychiatric Association, 2002) as other causes may be amenable to treatment. According to Coni et al. (2003) assessment involves establishing the likelihood of dementia, excluding other explanations for the clinical presentation, determining the type or cause of dementia, assessing any disability in daily living and identifying available resources. Assessment is a clinical approach that enables health professionals to recognise common disorders of old age, such as dementia, and improve outcomes for the individual and their quality of life. Assessment usually involves multiple team members, for example, medical officers, nurses, occupational therapists, social workers, psychologists or it may involve a combination of team members, for example, a medical officer and nurse who visit an older adult at home with the purpose of carrying out an assessment (Johnson, 2004).

As for any investigation, an accurate history of the problems that the individual has been experiencing is important. This may include a medical and psychiatric history, identification of any medications that the person is taking, any changes in functioning, and also areas of functioning that remain unchanged (Long &
Doherty, 2003). The Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975; Jacoby & Oppenheimer, 2004), a commonly used screening test for dementia, provides a useful initial impression about any changes in cognitive functioning. The MMSE comprises questions that test the person’s orientation, recall and language. A score of less than 23 (out of a total of 30) indicates that the person may have cognitive impairment (although those who are well educated may be dementing but perform well on this test, conversely, a person from a non-English speaking background may perform poorly but not have dementia) (Bentham & Hodges, 2004).

After confirming that the patient has dementia, the type of dementia needs to be identified. This may involve doing blood tests, for example, to rule out other reversible causes of dementia such as B12 deficiency, hypothyroidism, carrying out further clinical examinations and brain imaging, for example, Computerised Tomography Scan (CT) and Magnetic Resonance Imaging (MRI). However, CT and MRI imaging remain controversial and may not be helpful in identifying patients with a typical presentation of AD and where symptoms have been present for less than two years (Forstl & Hentschel, 2004). Coni et al. (2003) highlight that in the late stages of AD a CT scan usually shows cerebral atrophy, however, many patients in the early stages will have a normal looking scan. Moreover, imaging studies for Vascular dementia (VD) are also non-specific as many old people will have some degree of small vessel ischaemic disease on CT or MRI. However, as Landefeld, Palmer, Johnson, Johnston & Lyons (2004) point out,
where there is extensive ischaemic disease with multiple infarcts and a history of
europsychological findings indicating probable VD, then imaging findings will
probably be relevant. Positron Emission Tomography (PET) scans measure
glucose metabolism in specific areas in the brain and show promise in the early
diagnosis of AD. However, according to Sink & Yaffe (2004) their role in the
clinical diagnosis of AD is still largely unclear as they lack full sensitivity and
specificity in diagnosing AD. Brain scans, such as Single Photon Emission
Computed Tomography (SPECT), have also been developed to demonstrate any
hypoperfusion in cerebral blood flow. As Ratnaike (2002) points out, as with all
brain scan techniques, interpretation of findings may be affected by the overlap
between normal ageing, age-related memory loss and cognitive impairment
related to dementia, thus making diagnosis difficult.

As discussed earlier, evidence of cerebrovascular disease or focal brain damage,
may suggest VD, whereas lack of such telltale signs may by deduction lead to a
diagnosis of AD. Normal scan results do not mean that the older adult does not
have AD, however, the majority of people with AD usually show a loss of grey
and white matter volume (Forstl & Hentschel, 2004, p.268) as demonstrated on
CT scan.

Dementia occurs in Alzheimer’s disease (AD), in some types of cerebrovascular
disease (most common is Vascular dementia) and in other conditions such as
Lewy Body disease (LBD), Frontotemporal dementia (FTD), Parkinson’s disease,
and Acquired Immunodeficiency Syndrome (AIDS) that primarily or secondarily affect the brain (WHO, 2003). The more common forms of dementia will now be described.

2. 1. 3 Types of Dementia

In this section Lewy Body disease and Frontotemporal dementia, Alzheimer’s disease and Vascular dementia will described as they are the most commonly occurring types of dementia in the older population and of these Alzheimer’s disease is the more common type.

Lewy Body and Frontotemporal Dementia

LBD is a dementia characterised by fluctuating symptoms, episodes of acute confusion, prominent hallucinations, Parkinsonian symptoms and neuroleptic sensitivity, for example, to antipsychotic medications (Snowden, Neary & Mann, 2002). Recent studies, for example, Goh & Dhillon (2002) and McKeith (2002) indicate that LBD accounts for 15-25% of all cases of dementia. Moreover, Alzheimer-Type changes are also to be found in the majority of patients with LBD (McKeith, 2002) and up to one third of patients with dementing illnesses will have a mixed pathology (both AD and LBD) (Holmes, Cairns, Lantos, & Mann, 1999). It is not surprising, therefore, that there is an imprecise estimate of the proportion of cases of dementia due to LBD.
LBD is characterised by the presence of ‘Lewy bodies’ (Smith & Buckwalter, 2005) and displays a different pattern of cognitive decline compared to other types of dementia, with patients performing worse on tests of visuospatial activity, initiation of behaviour, and perseveration (persistence of repetitive verbal response or motor activity) (Harris, Nagy & Vardaxis, 2006). In addition, patients’ deterioration on the Mini-Mental State Examination is faster than for those patients with AD. Moreover, cholinergic deficits, for example, tremor, rigidity and bradykinesia, are more severe and occur earlier in LBD compared to those that occur in AD (Tiraboschi, Hansen, Alford, Merdes, Masliah, Thal, & Corey-Bloom, 2002). However, it is unclear whether LBD is a type of AD or is a disorder in its own right. It is possible that persons who are diagnosed with LBD are in fact suffering from AD and vice versa (Dugue, Neugroschl, Sewell & Marin, 2003).

Frontotemporal dementia (FTD) or Pick’s disease, is characterised by changes in the frontal and temporal lobes of the brain which control reasoning, personality, social behaviour, and speech (Smith & Buckwalter, 2005) thus resulting, among other things, in pronounced changes in affect and personal and social conduct (Del Ser, McKeith, Avand, Cicin-Sain, Ferrara, & Spiegal, 2002). FTD is characterised by the presence of ‘Pick bodies’ that gave the disorder its original name, Pick’s disease. However, these are not always present on autopsy, therefore, the term frontotemporal dementia has been used. Unlike AD, onset of FTD over 75 years of age is rare (Smith & Buckwalter, 2005).
Alzheimer’s Disease

As stated earlier in this section, AD is the most common type of dementia. The following discussion addresses the signs and symptoms, pathological changes, molecular biological changes and describes the parts of the brain involved in this disorder. The most common type of AD is the late-onset form (LOFAD), mostly occurring after 75 years of age (Coni et al., 2003). LOFAD is associated with genes that increase the risk of AD and it occurs over 65 years of age (Sink & Yaffe, 2004). There is a less common form of AD that occurs before 65 years of age (Jacoby & Oppenheimer, 2004) but this will not be described here as all wives in this study had developed the late-onset form.

Prevalence rates of AD vary and have been reported to occur in between 54% and 65% of all cases of dementia (Dugue et al., 2003, p. 47) with over 80% of residents in residential care and nursing homes experiencing the disorder (Ratnaike, 2002, p. 109). As noted in relation to LBD, there is considerable variation in the proportion of cases of dementia attributed to AD. As Dugue et al. (2003, p. 47) explain, comprehensive evaluations for AD are accurate 90% of the time but are sometimes not fully accurate until a post-mortem is carried out. This point is highlighted also by Esiri & Nagy (2004) who propose that to obtain the most accurate figures community based subjects need to be studied on autopsy and this, of course, would be difficult to do in all suspected cases.
In this thesis it is not possible to provide a detailed description of the pathological changes that occur in AD as its focus is on carers’ experiences associated with caring for wives with dementia. However, an overview is warranted so that the reader can develop some understanding of the disease process. Of note is the fact that its pathology is not as yet precisely definable as its components all occur to some extent in normal ageing and there is still no clear agreement about where normal ageing ends and AD begins (Esiri & Nagy, 2004) although generally it is agreed that the changes that occur are more numerous in AD. In AD, therefore, there are more senile plaques and neurofibrillary tangles to be found in the brain and it is thought that accumulation of plaques results in the formation of tangles (Coni et al., 2003). Accompanying these changes is a substantial loss of nerve cells and deficits in neurotransmitters.

Senile plaques are mainly distributed within the cerebral cortex, hippocampus, amygdala, nucleus basilis and locus coeruleus (Esiri & Nagy, 2004). Short and long-term memories are stored in the cerebral cortex. The former is stored for a few seconds or minutes and then consolidated by the brain and stored as long-term memories that can be retrieved later. Both types of memory are functions of various parts of the brain including the temporal, parietal and occipital lobes (Thibodeau & Patton, 2003). Memories of people seem to be stored separately to memories of places. It is possible that memories of people’s faces are stored separately again. It is possible, therefore, that in a person with AD some memories become affected and others are not (Seeley, Stephens & Tate, 2003;
People with AD have difficulty incorporating present experiences into long-term memory. They may also experience speech difficulties, particularly in relation to finding an appropriate word to use in conversation. Language comprehension is also affected, resulting in further problems in comprehension, reading and writing. When neurons are lost from the parietal lobe, especially the right side, the individual with AD becomes increasingly disoriented and frequently gets lost. Trouble with dressing may also be experienced as they are unable to correlate the spatial arrangement of their clothing with their bodies. Damage to the nucleus basalis is associated with changes in emotional states and intellectual function (Martini, 2004).

AD is characterised by an insidious or subtle onset and a gradual and progressive decline in function, for example, activities of daily living, although this is not always the case, and symptoms may fluctuate in presentation. Generally, life expectancy is shortened to a median life expectancy of 3-15 years (Sink & Yaffe, 2004). Significantly, there is an early, clinically silent phase spanning many years which is often only identified retrospectively, for example, by family carers. As noted earlier, the diagnosis of AD is only made after other causes are excluded. This can be achieved by taking a history, performing a clinical examination, carrying out special investigations including objective cognitive assessments, laboratory tests including biochemistry, complete blood picture, erythrocyte
sedimentation rate, thyroid function, and neuroimaging (CT, SPECT, PET scans) (Forstl & Hentschel, 2004), to exclude other explanations for the clinical picture (Hecker, 2002). A diagnosis of AD depends on clinically observable behaviours typical of dementia, and absence of evidence, either from the history and clinical examination or from laboratory tests, that the person’s mental state is due to other disorders of the brain (such as Parkinson’s disease or delirium) or other medical and psychiatric problems, for example, hypothyroidism, depression and drug reactions (American Psychiatric Association, 2002).

The presence of AD in at least one first-degree relative (siblings and children) has been found to increase the risk of dementia at least three-fold (although figures vary between 2.5 to 7.2 times) (St.George-Hyslop, 2000; Jacoby & Oppenheimer, 2004). There is also an increase in cases of AD where there is a history of Parkinson’s disease and Down’s syndrome, suggesting that a mutation on chromosome 21 results in the same tangles and plaques in the brain as are found in people with AD (Jorm, 2004). A mutation on chromosome 19 accounts for up to 40% of cases of late-onset AD. Search for a viral infective aetiology for AD, for example, herpes zoster, or environmental neurotoxin, has not as yet produced any positive results (Thomas & O’Brien, 2004).

A positive association between a low level of education, and risk for AD has been reported in a number of studies (for example, Caamano-Isorna, Corral, Montes-Martinez & Takkouche, 2006). Low educational level, however, may simply be
an indicator of social disadvantage which in turn increases the risk of malnutrition, perinatal or psychosocial damage at critical stages of development. Inquiry into a history of head injury suggests that resulting loss of consciousness, is a causal factor in some cases of AD (Jacoby & Oppenheimer, 2004). It can be concluded that genetic mutations and an earlier head injury have been positively implicated in the development of some cases of AD.

Another common cause of dementia is Vascular dementia. This is discussed next, its causes and risk factors, prevalence and ways in which it differs in its presentation from AD being highlighted.

Vascular Dementia

As described earlier, AD is the most common cause of dementia and accounts for more than half of the cases (although figures vary between 60-70%) (Sink & Yaffe, 2004). VD accounts for between 10% and 50% of all cases of dementia (Yates, 2002) and where AD and VD occur together, they account for between 14-60% of all cases of dementia (Hecker, 2002; Edwards, 2003). Such a wide range of case estimates highlights that there are differences in the ways in which VD is defined and measured by clinicians who are using different classification systems and therefore criteria to make a diagnosis (Yates, 2002). As discussed earlier, AD is caused by an accumulation of tangles and plaques which interfere with protein utilisation within the brain. VD, on the other hand, is caused by cerebral tissue
damage through large or small vessel disease, embolus or bleeding within the brain (Hecker, 2002) and is diagnosed when a person shows evidence of dementia and there is uneven deficits in memory, intellectual impairment and focal brain damage to various but specific parts of the brain, resulting from cerebrovascular disease and stroke (Sink & Yaffe, 2004) that is likely to be related to dementia. In addition, high blood pressure, lability of mood, relative preservation of personality (though some may show a definite change, for example, apathy, disinhibited behaviour, accentuation of previous personality traits), are often present (Thomas & O’Brien, 2004). Whilst the course of AD is insidious and progressive, the course of VD has been described as stepwise, that is, it is characterised by progressive episodes of deterioration (Hill, Schwarz & Sims, 2002). VD has several clinical syndromes. These syndromes are multi-infarct dementia (caused by a large number of small areas of infarction of the grey matter within the cortex of the brain), strategic infarct dementia (symptoms depend on location), and lesions in the white matter of the brain (Stewart, 2004).

There have been fewer investigations of risk factors for VD than for AD but direct risk factors include cerebral infarction, amyloid angiopathy, cerebral vasculitis, and intracranial haemorrhage. Indirect factors include essential hypertension, hyper-lipidemia, and a number of systemic diseases including diabetes mellitus (Alzheimer’s Australia, 2004). It may be noted that the incidence of VD increases with age and that where family members develop VD, the risk of close relatives also developing it increases. There is also some evidence that smokers are at
increased risk of stroke and therefore VD (Thomas & O’Brien, 2004).

Table 2.1 identifies the essential differences between VD and AD although these differences are not always as clear as the table indicates and as noted previously sometimes it may not be possible to diagnose AD, for example, until an autopsy is conducted.

**Table 2.1**

**Major Characteristics of Alzheimer’s Disease and Vascular Dementia**

<table>
<thead>
<tr>
<th>FEATURE</th>
<th>ALZHEIMER’S DISEASE</th>
<th>VASCULAR DEMENTIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Neurological Signs</td>
<td>Neuritic plaques, neurofibrillary tangles, loss of brain cells, reduced levels of neurotransmitters</td>
<td>Evidence of focal brain damage (weakness, abnormal reflexes, gait disturbances)</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Pattern of memory &amp; intellectual deterioration</td>
<td>“Patchy” deficits depending on area of brain damage</td>
</tr>
<tr>
<td>Cause</td>
<td>Not known</td>
<td>Stroke/transient ischaemic attacks (TIAs); often abrupt onset</td>
</tr>
<tr>
<td>Course</td>
<td>Progressive slow deterioration</td>
<td>Stepwise, fluctuating deterioration</td>
</tr>
<tr>
<td>Duration</td>
<td>Varies; average 8-10 years</td>
<td>Variable; average 8-10 years</td>
</tr>
<tr>
<td>Risk Factors</td>
<td>Age, family history, Down’s syndrome, head trauma, depression</td>
<td>Stroke, age, family history</td>
</tr>
</tbody>
</table>

(Adapted from Edwards, 2003, p.355)
Dementing illnesses are emerging as major health problems facing Australian society and are competing with heart disease, cancer and stroke for medical attention (AIHW, 2004). Disease burden refers to the range of effects dementia has on both the quality and length of life (AIHW, 2004, p.xiii). In Australia, dementia was the second leading cause of non-fatal disease burden for women in 1996 and the fourth for men (AIHW, 2000b.) and is projected to be the number one source of disease burden for women in 2016 and the fifth for men (Jorm, 2001). Burden in this context is the financial cost of services provided by State and Federal governments and private agencies, but does not include the costs to families who provide care. In Australia, Access Economics (2005) estimates that the cost of dementia in 2004 was $6.1 billion including $3.56 billion in direct health costs (mainly residential costs), around $1.96 billion in family carer costs, and the remainder in productivity costs, aids and modifications, for example, to the family home.

As highlighted earlier in this chapter, dementia, and Alzheimer’s disease in particular, is the main disabling condition for 2.6% of those aged 65-79 years, and for 12% of those aged 80 years and over (AIHW, 2000b.).

Prevalence refers to the number of new cases of disease that exist in a defined population at a particular point in time (Baum, 2001; AIHW, 2004). According to
Mayeux & Sano (1999) and Sisodia (1999) prevalence rates for mild dementia range between 2.4% and 12.7% and for severe or moderate dementia between 2% and 7.7% of older adults. Because of the difficulty associated with identifying people with mild or moderate dementia, no definite estimates of the number of people with various levels of dementia in Australia are available to date (AIHW, 2004). In Australia, 51% of people with dementia were living at home and 49% in nursing homes, hostels and other institutions (http://www.aph.gov.au/senate/committee). Worldwide prevalence rates have also been examined by age and vary in their projected estimations (see Table 2.2).

Table 2.2

Prevalence Rates for Dementia

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Prevalence Rates</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-74</td>
<td>2.8% to 5.7%</td>
</tr>
<tr>
<td>75-79</td>
<td>4.1% to 37.6%</td>
</tr>
<tr>
<td>80-84</td>
<td>10.1% to 56.3%</td>
</tr>
<tr>
<td>85+</td>
<td>13.3% to 72%</td>
</tr>
</tbody>
</table>

(Jorm, in Jacoby & Oppenheimer, 2004)

From Table 2.2 it is clear that prevalence rates vary widely. This is related to the use of differing study methodologies, sampling strategies and statistical analysis procedures, difficulties with distinguishing dementia from normal ageing changes, differences in clinical diagnostic criteria and researchers using different cut-offs.
on standardised measures of dementia (Jorm & Jolley, 1998; Sisodia, 1999; Long & Doherty, 2003; Access Economics, 2005). Even though there are variations in these figures, it is clear that the prevalence rate of dementia is much higher for the ‘old-old’ than for the ‘young-old’.

Because the population in Australia, and in many other countries is progressively ageing (Booth & Tickle, 2003), more people are falling into the age groups where dementia prevalence is highest. In 2001, it was estimated that over 165,000 Australians had dementia and this was projected to increase to 460,000 in 2040 (Jorm & Jolley, 1998). By 2050, it is projected that there will be over 420,000 Australian women with dementia (3.2% of all women), and over 310,000 Australian men (2.4% of men) (Access Economics, 2005, p.6). It is also clear that the number of people with dementia in Australia is well ahead of the increase in the population generally and for those aged 65 years and over (see Table 2.3). Table 2.3 demonstrates a steady increase in the overall population, pronounced increases in the elderly population and still more pronounced increases in the number of cases of dementia projected to 2005.
2.1.5 Treatment Approaches for Dementia

Treatment approaches for dementia have included medical and non-medical interventions, however, there is currently no intervention that can halt or reverse the progression of dementia. Nevertheless, a variety of treatment strategies are aimed at slowing the progression of the disease and maximising the person’s quality of life (Griffith & Arnold, 2005). Interventions often include a combination of medication, medical, psychological, environmental, behavioural, supportive counselling, and service provision.
**Medical Treatment**

Medical treatment of dementia involves the use of memory enhancing drugs that slow the onset of dementia. People with AD have less Acetylcholine, therefore, Cholinesterase (ChE) inhibitors are used in mild to moderate dementia to make more Acetylcholine available (Byrne, 2000). ChE inhibitors include Donepezil, Rivastigmine, and Galantamine and these, according to Bullock (2002) and Griffith & Arnold, 2005), have met with varying success. Apart from cost, another issue associated with their use is that where patients discontinue taking them they will return to previous dementia-related cognitive levels (Byrne, 2000; Sink & Yaffe, 2004). It has also been suggested, for example, by Bullock (2002) that vitamin E, oestrogen, and anti-inflammatory agents show some promise in the treatment of Alzheimer’s disease but there is insufficient evidence to support their routine use (Byrne, 2000; Sink & Yaffe, 2004). More recently, Memantine has been used to treat late-stage dementia and this medication regulates the activity of glutamate, a neurotransmitter, which is essential to learning and memory. Although it won’t reverse the disease there is some evidence to show that it may slow the process and improve awareness in some people. This finding highlights the need to diagnose dementia early so that drugs may be used more beneficially before the moderate to severe stage when they will be less effective (Bullock, 2002). Non-cholinergic treatments, such as ginko biloba (an anti-oxidant) have been proposed as being beneficial for the treatment of dementia. According to Sink & Yaffe (2004) ginko biloba may have some effectiveness in mild dementia.
No drug therapies have been specifically useful for VD. Treatment of stroke risk factors remains important, especially cessation of smoking, reduction of hyperlipidemia, and treatment of diabetes. A range of strategies include modification of diet, removing arterial blockages, aspirin, cholesterol and high blood pressure lowering agents (Griffith & Arnold, 2005). However, once dementia is present, mild hypertension (systolic readings in the 150s mmHg) may benefit cognitive function. Some data suggest that galantamine in VD may benefit cognition but according to Landefeldt et al. (2004) more studies are needed.

At the time when the present study was carried out, memory enhancing drugs were not on the Pharmaceutical Benefits Scheme (PBS) and were therefore very expensive. Since the study ended several drugs have been included on the PBS and are affordable for most carers. During the study several wives had been included in trials of new memory enhancing drugs.

**Psychological, Environmental and Behavioural Treatments for People with Dementia**

In psychological treatments the individual with dementia is encouraged to take part with others in activities, for example, reminiscence, reality orientation. These interventions are believed to improve cognitive function, mood and behaviour although the changes may be short term and may or may not prove to have any
lasting consequences as the disease progresses (Grasel, Wiltfang & Komhuber, 2003; Smith & Buckwalter, 2005).

The psychosocial environment of the older adult with dementia should encourage interactions with others and be stimulating through a variety of experiences that call for some personal initiative or self-expression. It should provide opportunities for personal choice in relation to dress, privacy and personal possessions and reinforce a sense of personal dignity, discourage excessive sleep and allow a range of activities in safety and under appropriate supervision. At the same time, the physical environment should be structured to allow for predictability, calmness, and safe wandering. Although such an environment will not necessarily bring about any lasting cognitive benefits, it should assist the development of a better quality of life for people with dementia.

The cause or causes of disturbed behaviour should be identified and where possible eliminated or modified. Environmental change may be implemented to effect change in behaviour, for example, use of colour coding for various rooms and signs or pictures on doors (for example, a picture of a toilet for the room that houses a toilet. A behavioural approach, for example, rewarding appropriate behaviours and ignoring inappropriate behaviours, may be effective if the person’s memory impairment is not too advanced (Lai & Arthur, 2003). Nevertheless, change of any kind is unsettling for the person with dementia, since there is a sense of security in stable long term memories of activities, people and events.
Sensory enhancement, for example, Snoezelen Therapy (multisensory therapy using music, colour, tactile, smell and touch), music, aromatherapy, simulated presence therapy, (SPT), and structured activities have also been utilised in clinical practice (Smith & Buckwalter, 2005) but may also be of use to family carers. Evidence of the effectiveness of Snoezelen is still unclear but there have been some reports of its usefulness in some people with dementia in residential settings (Wallace & Brown, 2000).

In SPT, it is thought that patients’ agitation is decreased and social interaction increased by audio-taping personal conversations and memories, and family anecdotes. Significant improvement in social isolation has been demonstrated in some studies but not for all participants (Smith & Buckwalter, 2005). Music therapy may be effective in reducing challenging behaviours in older adults with dementia but results may depend on the importance that music had for them previously (Heim, Nair, Mowbray, & Tavender, 2003). Aromatherapy therapy has also been shown to be effective in reducing challenging behaviours in some patients particularly where it is used in combination with massage and touch therapy. However, a person’s response to aromatherapy will depend on the positive or negative memories the smells trigger. The use of structured recreational and physical activities is thought to alleviate boredom and therefore agitation but, as Kolanowski, Litaker & Buetter (2005) point out, this will not be a very effective approach in patients with late-stage dementia.
Supportive Counselling and Supports for Family Carers

Particularly when home-based family care is provided, supportive counselling or supportive psychotherapy will allow family members who are providing care to ventilate feelings and deal with their own concerns and those of other family members (Mittelman, 2003). The carer and other family members may need advice, for example, about power of attorney and guardianship. Support group attendance often provides emotional sustenance and education (Dellasega & Haagen, 2004). Some randomised trials have shown that carer support groups have delayed institutional placement significantly (Cooper, 2002).

Determination of the level of disability and the identification of supports and resources available for persons with dementia and their carers is important and has implications for the type of management plan that is developed. These determinations are often carried out by allied health professionals, for example, Nurses, Occupational Therapists, Social Workers, Psychologists, who are members of the multidisciplinary team. The level of the person’s disability may be assessed using instruments which assess activities of daily living (ADLs), for example, drinking from a cup, eating, dressing, washing, bathing and grooming (GPnotebook, 2003), and instrumental activities of daily living (IADL), for example, ability to use a telephone, shop, prepare food, do housekeeping and travel independently (Weiner, Gehrmann, Hynan, Saine & Cullum, 2006). Formal supports, for example, hospital services, home care, and informal
supports, for example, family, friends, support groups, should also be identified and assessed for the level and quality of support that is being provided or has the potential to be provided.

To allow optimum independence for the person with dementia and provide support and backup for family carers, a variety of supports, for example, home care, day care, respite care, meals on wheels, home maintenance, may be arranged following an evaluation of the premises (house and surrounding areas, fencing and gates) and the particular needs of the person receiving care. Respite may also be provided in nursing homes, but needs to be sought and booked well ahead of time. Respite may also be provided at home. It enables family carers to have a holiday from intensive caring (Department of Health & Ageing, 2006).

However, measures of practical help to carers have seldom been evaluated (Cooper, 2002) and little is known about male carers’ use of formal support services (Coe & Neufeld, 1999).

2.2 Summary

In summary, dementia is a significant, degenerative and irreversible disorder of brain function which eventually leads to death which may result from respiratory infection simply because the person with advanced dementia forgets how to cough. The incidence of dementia increases with age, and its highest incidence occurs in the seventh and later decades. Sufferers experience profound changes in
thinking, memory, orientation, emotions, personality, judgment and ADLs although the level of change in each area of behaviour may vary within and between individuals. Problem behaviours associated with these changes become worse as the disease progresses. Problems may also be related to the presence of psychiatric illness, medical problems, the personality of the sufferer and the environment in which the family member is being cared for. Dementia results in an increasing number of disabilities over time.

Common causes of dementia are Alzheimer’s disease and Vascular dementia and the number of people in the Australian population who develop these diseases will continue to increase well into the future. Many family members, spouses in particular, are providing care for relatives at home and face multiple problems associated with dementia. Treatment approaches for both AD and VD do not halt or reverse the progress of these illnesses although memory enhancing drugs may assist cognition in some persons with dementia. Therefore, environmental and behavioural interventions for challenging behaviours take on increasing importance. Supportive counselling for carers allows them to deal with feelings and concerns associated with providing care. Various services provide support for carers. However, the efficacy of supportive counselling and support services for male carers is not well researched.

The next section of this thesis will examine care giving in Australia and in particular explore what is known about older husband-carers of family members
with dementia.

2.3 Disability, Dementia and Caregiving in Australia

As discussed earlier in this chapter, dementia is an important cause of disability in the older population. In 2003, the ABS (2002) survey of disability identified that one in five people in Australia (3,958,300) had a reported disability. This rate was much the same for females (20.1%) as males (19.8%). Disability usually exists as a consequence of disease, disorder or injury which causes any restriction, limitation, or impairment which has lasted, or will likely last, for at least six months (AIHW, 2000a.). Disability results in restrictions in everyday activities (ABS, 2003). In an ABS (2001) report, fifteen percent of people with a disability identified a mental or behavioural disorder (including dementia) as their main problem.

In relation to older Australian adults, in 2002 there were 3.25 million people aged 60 years and over and just over half (51%) of this number had a reported disability and 19% had a profound or severe core-activity (includes restrictions in mobility, self-care and communication) limitation. Of all people aged 60 years and over, 41% reported needing assistance, because of disability or old age, to manage health conditions or cope with everyday activities. People aged 85 years and over have reported a much higher need for assistance than those aged 60-69 years of age (ABS, 2003). People with a mental or behavioural disorder are more likely to
be profoundly or severely restricted than those with a physical condition, for example, with arthritis. The vast majority of people with dementia (94%) have been found to have profound restrictions. Disability is associated with decreased labour force participation and decreased income and increased care support (ABS, 2002).

In 2002, more than half (56%) of those who were providing care for people with a disability or aged related decline were female although a significant number (44%) were males. Primary carers (for example, a family member), are those carers who provide the most informal assistance with personal activities to a person with a disability and therefore caring plays a major part in their lives (ABS, 2003). In 2003, 2.6 million carers provided some assistance to those who needed help because of disability or age. About 19% were primary carers and just over half (54%) were women. Thirty-nine percent of these were in the 35-54 year age group and they were providing care for children, partners and/or ageing parents (ABS, 2003). This report highlighted that 79% cared for a person in the same household. Where people with a disability needing assistance were living in the same household, this was provided by relatives and friends, partners, parents or children. Partners, sons and daughters were the most common providers of help to older people. Of the older people receiving formal assistance, 452,000 (47%) were assisted by partners, who were also likely to be older themselves. A Government pension or allowance was the main source of personal income for about 74% of people aged 60 years and over living in households with a
disability. The most common reasons given by primary carers for taking on the caring role were family responsibility, the belief that they could provide better care, and a sense of emotional obligation. Thirty-seven percent of primary carers reported spending on average 40 hours or more a week providing care (ABS, 2003).

Sixty-one percent of family carers reported they assisted with the management of the disabled person’s health conditions and activities of daily living for 3.8 million people with a disability living in the same household. At least 22% reported that their needs were only partly met, and 3% that they were not met at all. Those who were experiencing a core-activity limitation and who had a more severe disability, reported a higher proportion of unmet needs for help (ABS, 2002). Little is known about the care giving experiences of family members from a non-English speaking background and a summary of what is known is provided next.

Caring for People from a Culturally and Linguistically Diverse Background (CALD)

According to Hinton (2002), the exact number of CALD carers in Australia is not clear although a crude estimate is that there are 110,000 to 120,000, of whom about two thirds speak a language other than English at home. Of these, 85% live in eight capital cities, more than three quarters live in NSW and Victoria, and two
thirds in Sydney and Melbourne. More than two thirds of CALD carers are women. He further states that this figure is higher than that for the general population. It has been reported that 15.4% of people with disabilities are from CALD backgrounds (Ethnic Disability Advocacy Centre, 2005). It is unknown from the literature review how many of these are older people.

Various researchers (for example, Rice & Walker, 2005) and carer organisations (for example, Carers Australia, 2006) have reported that there is considerable diversity among CALD carers in relation to personal circumstances: caring situations, feelings about their role as care, cultural beliefs, practices and influences, circumstances of migration and settlement experiences, family structures, individual and family attitudes towards mental and physical illness and disability, attitudes towards seeking help from outside the family and family members’ expectations about who the carer should be. English language skills and lower literacy skills add additional strains. Cultural and language barriers may prevent CALD carers from seeking support from formal support services. Moreover, it has been suggested by Fischer (1995) that cultural factors may influence conceptions of dementia, family decision making, expressions of care giver burden, dementia care and service utilisation. Additionally, disability and illness may be a source of shame and embarrassment and, therefore, may be covered up and responses to caring and disability may lead carers to feel extremely stressed, isolated, and lonely. However, few studies have examined the occurrence of dementia-related behavioural problems and their management in
ethnic minority families (Hinton, 2002) and their subsequent effects on carers (Ethnic Disability Advocacy Centre, 2005).

In stage one of the present study, thirty-seven percent of husbands were born overseas and comprised thirty-five percent of study participants in stage two.

There is also a lack of generic and specialist services in rural and remote areas of Australia and family carers in these contexts are disadvantaged in accessing the services that exist. In addition, Aboriginal and Torres Strait Islander populations experience these and other problems.

**Carers from Rural, Remote Areas and Aboriginal and Torres Strait Island Communities**

In rural, remote and Aboriginal communities respite care and day care services are in short supply and there is some difficulty in recruiting health workers to provide support for family caregivers in these communities (Australian Government, 2005). Service waiting lists are long and indefinite and eligibility criteria may further restrict service availability. Transport and phone service costs can be significant, isolation may result and rural 'self-reliance' prevent utilisation of available services. In addition, lack of information about services may be a problem and support groups may be inaccessible or absent (Brown, 1995). Australian rural women’s access to health services has been a particular problem
Burdens associated with providing care for a family member in rural areas are increased where support programmes are under-resourced and poorly developed (Hazleton, Habibis, Schneider, Davidson & Bowling, 2004). Hazleton et al. have suggested that health service personnel who are providing support to family carers could be further supported by providing telephone-based support, and advice and access to technologies such as telehealth delivered from the main metropolitan centres.

Information about the experiences of Aboriginal and Torres Strait Islanders who are carers of people with dementia is inadequate. Moreover, little is known about dementia in aboriginal populations. This is probably related to the fact that insufficient numbers of aboriginals move through into old age, where the prevalence of dementia is at its highest, since they have high mortality rates in earlier ages due to heart disease, renal failure and other medical consequences associated with diabetes mellitus (AIHW, 2000b.). There were no carers of Aboriginal or Torres Strait Islanders in either stage of the present study but this could be an important phenomenon to study in future research projects.

According to Cox & Spalding (1995) interest in care giving by researchers and others is of recent origin. Since their article was published, there has been an
increasing interest in care-work and this has been reflected in an increase in articles in scholarly journals.

2. 3. 1 Carers and Care-work

The increased interest in care-work by researchers and others may be related to several factors. As it has already been highlighted, care work has essentially been women’s work. Kendig (1994) and Alston et al. (2006) have proposed that the interest on care giving occurred at the same time as the development of the women's movement which gave rise to an increased focus on women and their experiences. Alston et al. in particular believed that the increased focus developed as a response to the ideological shortcomings within the medical approach to women’s health care. Alternatively, Cox & Spalding (1995) have hypothesised that it may have been related to a response to government policy shifts which included a commitment to reductions in government services and spending on services. An example of the latter explanation was highlighted in the measures introduced by the Commonwealth Government in the mid-1980's, following the McLeay Report (1982) into what the government perceived as a proliferation of nursing homes. The Report recommended that there be reductions in the building of nursing homes, a limited expansion of hostels, growth in community support services through Home and Community Care funding, and a significant increase of expenditure associated with the development of Geriatric Assessment Teams throughout Australia, comprising staff from various health
care disciplines. These measures were aimed at reducing the eligibility of older people for nursing home and hostel care through uniform assessment procedures and reflected in large measure the financial cost associated with providing residential and acute inpatient care, this figure was later estimated to be $4 billion annually (ABS, 2004). The Federal Government’s social policy since 2001, as reflected in community care policies, has encouraged those who need assistance to remain at home via the provision of information, respite service and community care packages (Dicker, 2001). Providing care for many older adults with dementia has effectively meant, therefore, being cared for by family members at home and in particular by women. A second hypothesis for the increased focus on family care giving, therefore, proposes that since the number of informal carers providing care at home to family members has increased significantly because of government policies, health professionals, researchers and governments have been forced to examine their experiences, needs and problems, and health professionals and governments have had to provide support services for them.

A review of the carer literature highlights that carers receive various supports and services. However, even where formal supports, for example, community nursing, home care, meals-on-wheels, are available, family carers often require additional assistance from informal sources, including other family members, neighbours and friends. However, the extent to which formal service providers treat family carers as active participants in care provision is largely unknown. The writer is aware that over recent years care givers have become increasingly
involved in the decision-making process associated with the allocation and
delivery of support, through such local organisations as the Alzheimer's and
Carers' Associations. As early as 1995, the Department of Health and Community
Services, Victoria, reported that family carers are more and more seeking out
information for themselves to assist them in their care giving efforts. But, who
are the family carers?

Family Care givers: Who are they?

Carers are variously defined and described in the literature. This creates a
problem for governments when increasing attention is being given to the
development of social policies directed towards them and those for whom they
provide care. Moreover, how the carer is defined determines how that individual
is identified and studied by researchers. Definitions of care givers from the
research literature will be described in Chapter Three. However, unless some
consensus is reached about who is a carer it will be difficult to provide the care
and financial support they may need. What is known so far from the information
provided in this chapter about their characteristics?

It is clear from the previous section that the majority of family carers are women,
and spouses and adult daughters provide the main sources of help for people with
dementia (AIHW, 2000a.; Mittelman, 2003). Spouse carers are more likely to be
retired and living with the person for whom they are providing care (AIHW,
However, it is worth noting that care giving is often cross-generational, for example, an elderly woman who is providing care for her husband often receives varying degrees of help from adult children and grandchildren, friends and neighbours.

Carers for people with dementia have been reported to be generally somewhat older than other carer groups with ages ranging from the 30s to the 80s and mean ages in the 60s. Specifically, in relation to carers of people with dementia, there are two major age groups as follows: adult children whose mean age is in the 50s, and spouses whose mean age is in the late 60s and early 70s (ABS, 2003).

It is not surprising that much of the dementia literature has focussed on the care giving experiences of wives and of daughters (Mays et al., 1999). Several theories have been proposed to explain this. One explanation is that women have been socialised into the carer role. The argument here is that female carers, especially elderly spouses, were raised in an era in which females were socialised to be more family-oriented (Archer & MacLean, 1993) and many, therefore, took on a nurturing role within and even outside of the family. The role of carer in later life for women, therefore, may be seen as a continuation of this traditional role and may also explain why women give higher priority to domestic demands and caring and nurturing roles (Houde, 2001) than men do. Another explanation could be that women have been available to care for family members in need since they remained mainly at home and could provide 'free' care (Mays et al.,
Since the 1960’s and 1970’s women have been influenced by demographic and economic changes with many more of them entering the workforce. For example, middle-aged women in particular are increasingly faced with multiple responsibilities including job demands and demands of the immediate family as well as care for dependent parents (Parsons, 1997; Gallicchio et al., 2002). Australian researchers, Cox & Spalding (1995) have suggested that female carers have been unlikely to be able to trade off work for leisure or other activities as they have earned less than men or never worked at all. This proposition suggests that care giving might be related not to choice but to their ability to earn or otherwise. For example, if a female carer was receiving an adequate income she might be able to choose to employ someone else to assist with care giving. The reality is that in the past, many more women than men, have had to take a less responsible job and unpaid leave related to their care giving responsibilities.

Another possible explanation for the preponderance of women as carers is that women's life expectancy has been longer than men’s and more women than men (ABS, 2004a.) were therefore available to provide care. It is also noteworthy that men generally marry younger women (ABS, 2002) who are then available to provide care when men reach those ages where diseases, such as dementia, are more common. It is interesting to note that an increasing number of older men are providing care for female partners with dementia (Houde, 2002). When attempting to define family carers, men, therefore, will have to be included in the definition in relation to government policy development and researchers will have
to examine their experiences and whether these are different to those of female carers. There are, however, a few research studies that have examined their experiences.

**Men as Carers**

It has been estimated that between 33% (Neufeld & Harrison, 1998; Coe & Neufeld, 1999) and 44% (AIHW, 2000b.) of family carers are men and most of these are husbands. This disparity in estimates perhaps highlights again that there are different ways in which care givers are defined by researchers, but according to Cox & Spalding (1995) male carers are most likely to be older men who are providing care for wives at home. However, there has been a lack of research-based knowledge of their needs and experiences. It is unknown, for example, how well men accept this role. To begin to examine their experiences of care giving, the writer believed that it was necessary to begin by reviewing the perspectives that explain the ways in which men are socialised within a society such as ours and this requires some discussion of the concept of masculinity. This will be explored in the next section and in particular the implications of the different perspectives for male care giving discussed.

One approach to the concept of masculinity is that of McDougall (1997) who suggests there are different perspectives about the concept of masculinity (or ‘multiple masculinities’). He proposes that there is the conservative or traditional
perspective which highlights that males assume that they have a right to be both politically and socially dominant both in the world of work and within the home sphere. McDougall identifies that there is also a perspective that is sympathetic to feminism and acknowledges that masculinity is created through male privilege and its corresponding oppression of women. Many men, therefore, might encourage wives to work outside the home and might themselves care for their own children. A third, the socialist perspective, highlights that masculinity is determined by who does the work, what work is done by males and females, who controls the labour of others and the products of that labour. We might find, for example, within the generation of older people which is of interest that the distribution of labour within the husband-wife relationship is fairly fixed with wives and husbands carrying out very different roles both within and outside of the family with little movement between these roles.

Differences in perspectives about masculinity highlight that ‘masculinity’ is a difficult term to define and can mean different things to different interest groups. Connell (1999) suggests that this is related to the character of gender itself that is “historically changing, politically fraught and claimed by conflicting discourses and systems of knowledge” (p.3). An alternate interpretation is one that was suggested by Greig, Kimmel & Lang (2000) who argue that the existence of different perspectives highlight that there are many ways to be a man.

Another approach to the concept of masculinity highlights that there are two
perspectives which describe how men are socialised into their masculine roles. According to the perspective that emphasises biological destiny, masculinity refers to those innate qualities of men that distinguish them from women.

Masculinity, therefore, is seen as a genetic predisposition and any advantages they might have, for example, physical and political and economic strengths, reflects these advantages (Greig et al., 2000). The writer believes that the problem with this view of masculinity is that it all too conveniently explains men’s political, economic and cultural advantages in terms of their natural superiority and obscures other explanations.

The other broad perspective identifies that masculinity is not a ‘fixed’ concept but is constructed over time (Connell, 1999) and is a product, therefore, of socialisation. Kaye & Applegate (1990c.), writing in agree with this perspective and argue that the establishment of a core gender identity leads boys and girls to develop differently, resulting in two distinct worlds. According to these writers, girls are able to establish a female self-definition while at the same time retaining a primary identification with their mothers whilst boys must forcefully separate from their mothers in order to identify with their fathers so as to consolidate their maleness. Gallicchio et al. (2002) affirm this interpretation and propose that during western sex role socialisation parents treat girls in ways that foster connectedness with others and encourage separation and distancing in their boys. Accordingly, through this process masculinity becomes associated with ‘getting the job done’ and involves separation, while femininity evolves into a concern for
the wellbeing of others. Thus, men become a worker outside the family rather than a nurturer within the family (Morris, Woods, Davies & Morris, 1991). When male carers’ experiences are studied therefore, we might find that they approach care giving as if it is a job to be done and experience problems with the more nurturing aspects of care giving, for example, meeting the intimate and personal care needs of their wives. In terms of care giving then, being in charge of or managing another person, for example, a wife, who has a dementing illness, may be seen as an extension of the male role as an authority figure in the home or at work rather than an extension of the nurturing role. If this argument is correct, we could expect to find that men will transfer a scheduling and task oriented approach from work and be at ease with the more instrumental aspects (characterised by efficiency, planning, being organised) of care rather than the affective ones as proposed by Harris (1995) and Coe & Neufeld (1999).

An interesting extension of the ‘socialisation’ perspective of masculine development, is one that proposes that developmental changes in sex role differences may continue to occur during middle age and later life (Guttman, 1987). Evidence for this idea may be found in an earlier study by Fitting, Rabins, Lucas & Eastham (1986) who described that the husband-wife relationship had improved since the onset of the dementing illness. There is some evidence also to suggest that men might be more ready for a new and challenging role after retiring from work (Archer & MacLean, 1993). It is also possible that more flexible conceptions of sex roles have afforded men more opportunities to express
nurturing through care giving as proposed by Kaye & Applegate (1990c.), Carlson & Roberston (1993) and Harris (1995). Some men, it has been argued (Morris et al., 1991), experience positive feelings from ‘repaying’ their wives for past nurturing, or try to assuage their sense of guilt associated with their feelings that they have contributed to an unhappy marriage or have not contributed much at all.

As described earlier, there are different perspectives of masculinity. However, MacDougall (1997) argues that for many husbands, the overwhelming image of masculinity remains traditional and dominates all areas of men’s lives. If this argument is accepted, even where men try to create new ways of thinking and doing they will often return to former roles within the workplace and home and even if some men are changing, this does not necessarily mean they are taking on more caring behaviours.

2.4 Summary

Care giving generally has been the responsibility of wives and adult daughters. Over recent years, and for various reasons, more males have begun to assume the role of care giver. It could be that males approach care giving as they would have approached their experiences as a worker. Another possibility is that sex role changes keep occurring and that men, who are providing care, experience more flexible conceptions of sex roles over time and care giving offers opportunities to express nurturing.
At the time this study began there was a lack of research of male carers’ experiences generally and older male carers’ experiences in particular and it was unclear whether they used a more instrumental approach to care giving or were more nurturing. There was ample evidence from the literature review that many family carers experienced the role negatively. For a few it was a more positive experience. Little was known about the ways in which males experienced their role as carer.

Positive and Negative Responses to Care giving

Surprisingly, for some older husbands of wives with dementia, care giving is perceived to enhance and enrich their lives. Archer & MacLean writing in 1993, reported that male carers found care giving to be emotionally gratifying and satisfying. However, subject numbers were small and consisted of both husbands and sons making it difficult to identify husbands’ specific responses. Harris (1993) also identified that where husband-carers were able to take control and problem-solve to bring about positive changes in relation to their care giving, they developed a sense of personal efficacy and felt rewarded. For the older male carer one explanation for these findings is that care giving provided a new and distinct role from work in which another individual was dependent on him (Kramer, 1997) for their needs to be met rather than working under others. Other possible explanations are that it allowed older men to express nascent sex-typed qualities such as caring and nurturance (Guttman, 1987) or provided them with an
opportunity to redefine themselves as being separate from the work role or ethic (Kramer, 1997). The present writer is of the opinion that it is important, even to men, to keep the family and marriage intact rather than seek early placement of their wives in an institutional setting. However, it is unclear, from the literature, whether the perceived positive consequences continue as the illness progresses or whether the issues are the same or different in some ways for male and female carers. There is an increasing amount of evidence in the literature that both groups of carers experience a sense of burden and some become depressed as time goes by.

Burden is a commonly experienced phenomenon associated with family care giving, and is defined in various ways. Burden has been described as having a subjective aspect to it, that is, it is related to the carers’ feelings or evaluations of care giving activities, events and experiences, and taking on new roles (Coe & Neufeld, 1999; Kramer & Lambert, 1999). It has also been described as having an objective component to it, that is, it results from the demands of the care giving role and is related to the way in which, for example, wives’ problem behaviours impact on the caregiver (Parsons, 1997; Kramer, 1999), for example, when wives ask the same question repeatedly it makes husbands angry and frustrated. A third way of looking at the phenomenon of burden is proposed in this study and highlights that it results from the tension created by the effects of the demands of care giving on carers’ ability to meet their own basic needs.

Various studies have reported that carers of family members with dementia
commonly experience depression and an increased sense of burden associated with their care giving role and associated activities. Depression has been described in some studies as occurring to varying degrees or levels, from mild to severe (Rose-Rego, Strauss & Smyth, 1998; Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry, 2001). Other studies, for example, Schulz, Visintainer & Williamson (1990) have described that family carers may experience depressive symptoms but may not have been clinically depressed. Examples of this, could include that the carer is unhappy (Kramer & Lambert, 1999), or sad (Butcher, Holkup & Buckwalter, 2001), or grieving (Morgan & Laing, 1991). Such descriptions of these consequences associated with care giving are usually reported in qualitative studies of carers’ experiences although there have been few attempts to measure them quantitatively.

Dementia inevitably impacts on immediate and extended family networks as well. Sammut (1995) provides a useful list of factors that may impact on the family members’ responses to the development of dementia in one of its members. Individual factors include the position of wives and husbands in the family; the roles and tasks both have performed, and their power and status in the family prior to the illness. Family factors include the nature of family boundaries within the family and between family members and the outside world, and the family’s ability to adapt to change. The developmental phase of the family will also have an impact. Resources and support available to the family and the family’s willingness to utilise these and whether family members live with the affected
person, may also influence their responses as well as their ability to adapt to the changes that have occurred in the person with dementia.

The development of dementia in a family member may lead to role reversal (husbands may have to take on wives’ roles), reduced carer time for care giving for other family members, feelings of guilt, resentment about their significantly changed circumstances, and fear of the future. For many, it may lead to reduced personal time. Balancing care recipients’ autonomy with having to ‘take over’ some of the affected person’s roles, withdrawing from contact with other family members, including withdrawing emotional and practical support, will also be a challenge for carers. Old, unresolved conflicts between family members may resurface, and the family carer may struggle to keep up other responsibilities such as work (Ohaeri, 2003).

2.5 Conclusions

Dementia is a major health problem in Australian society. Sufferers experience significant changes in memory, thinking, orientation, learning capacity, language, judgment, personality and activities of daily living. There are various causes of dementia but the most common is Alzheimer’s disease and there is no known effective treatment for it. Prevalence rates are highest for the old-old. Presently, over 250,000 Australians have dementia with nearly half of them being cared for in the community. All husbands in the present study reported that their wives had
been diagnosed as having either Alzheimer’s disease or Vascular dementia although as discussed earlier in the chapter, some may have been experiencing a Lewy Body dementia.

Changes in cognition, behaviour, emotions, personality and activities of daily living, make care giving difficult for family members. Formal interventions for family carers include supportive counselling, home, day and respite care, meals on wheels, home maintenance, and support groups although not all carers take up these opportunities. Informal support is provided by family members, friends and neighbours. It was unclear from the literature how helpful these supports were for older males who were providing care.

Interest in care-work has focussed on the experiences of women carers most of whom are wives and adult daughters even though male carers comprise up to 33% of carers in research studies. However, little is known about male carers’ experiences generally and older husband-carers’ experiences of the role in particular. Additionally, there is little information about males’ experiences in rural and remote areas and Aboriginal societies although the latter was not investigated in this study.

Negative consequences related to care giving have been reported in the literature including the development of depression and an increasing sense of burden related to the carers’ workload associated with the sufferers’ decline, lack of resources
and support, and whether older males as a group of carers of wives with dementia experienced similar problems and if they did, what these were related to.

Men’s ideas about what behaviour is expected of them in the care giving role will be strongly influenced by sex role socialisation. Many men from the generation of interest in this study were socialised to establish their identity outside of the home. This may go a long way to explain the negative reactions of many of them to care giving. However, some husbands accepted the care giving role more easily and these were likely to describe that they were encouraged by their parents to sew, cook, wash, iron for themselves and some had also been involved in the upbringing of their own children.

The purpose of the present study was to contribute to our understanding of the phenomenon of husbands’ care giving experiences associated with providing care at home for wives who had been diagnosed with dementia. Little was known, for example, about the characteristics of older husband carers and of their needs and problems associated with caring. One reason for this apparent neglect suggests that men play a limited role as carers. Such a conclusion, however, is hard to accept because it has already been noted that men carers have comprised up to 33% of study sample numbers. Moreover, it is likely that increasing numbers of males, especially husbands, will assume the carer role as more women are diagnosed as having dementia and greater numbers of middle-aged women who would normally provide care enter the workforce or pursue new interests,
including study, part-time, casual or full-time work.

In the next chapter the present state of knowledge of the care giver literature is examined. Findings are organised under four categories, first, information about those studies that focussed specifically on male carers’ experiences is analysed, secondly, those that examined the differences between male and female caregivers’ experiences, thirdly, carers’ studies which examined carers’ experiences generally and reported some findings for male carers, and finally, those that explored the experiences of male and female carers and reported findings more generally.
CHAPTER THREE
LITERATURE REVIEW

The literature review indicated that there were few overseas studies of older husbands’ care giving experiences associated with providing care for wives at home who had been diagnosed with dementia and none in an Australian context. Within this chapter concepts of carer and carer burden and depression are examined.

Introduction

In examining the literature relevant to a research topic the investigator initially identifies terms and concepts of primary and then secondary importance. Hard copy and electronic sources are explored in the most obvious data bases, and depending on the results, the net may need to be cast wider. The purpose is to identify what questions have been asked and answered and importantly, those that remain unanswered. Search terms used in the initial review included male carers/care givers; female carers/care givers; family carers/care givers; family care giving/care giving; dementia/Alzheimer’s disease/Vascular dementia/cognitive impairment; burden/strain/stress/depression and family care/care giving. After culling, forty articles were considered relevant.

This chapter describes and critiques these studies, their methodologies and findings as well as associated scholarly literature on carers of people with
dementia, and on male carers whose wives had dementia. It begins with a
summary of studies of male, female and family carers. It then proceeds to
examine studies which point out differences in the experiences of male and female
carers, summarises the findings, and distinguishes areas for further investigation.
Thirdly, it examines studies of carers’ experiences more generally and highlights
any findings reported for males.

3.1 Research Studies on Carers of People with Dementia

Examination of the research literature, using CINAHL, MEDLINE,
PSYCHINFO, OVID, in relation to family carers and care giving indicated forty –
three articles published between 1983 and 2006 based on research studies of care
givers’ experiences associated with providing care for a family member at home.
Four broad types of studies (Table 3.1) were identified as being of some relevance
for the present study. They were clustered for convenience and named by the
researcher as Category One, Two, Three and Four studies.
A total of thirteen category one studies were identified through the literature review that had focussed on the topic of interest for this study, males’ experiences associated with providing care to family members and others. Studies were published between 1984 and 2000. This indicated that there has not been a sustained and consistent interest by researchers in studying male carers’ experiences, although there was no information identified about unpublished
research. Of the thirteen studies, nine were carried out in the U.S. and four in Canada. There were no Australian studies of the phenomenon of interest in the research literature. Eight studies focussed on older husbands’ experiences associated with care giving for wives. The remaining studies examined the experiences of males, including sons and spouses who were providing care for others. Only four of the studies had examined the care giving experiences of older husbands who were providing care for wives at home with dementia and no studies of this topic had been carried out in an Australian context.

Category One studies are reviewed first in the next section. The review highlights that many males experienced a sense of burden associated with care giving and a number of studies reported what this phenomenon was associated with. Fewer studies have focussed on males’ experiences of depression in a family care giving context.

3. 2 Category One Studies

There were thirteen studies that had focussed on male carers’ experiences. Studies had employed qualitative or quantitative paradigms, or a mixture of the two to investigate what it was like for males to provide care. Qualitative studies utilised phenomenology (Parsons, 1997; Siriopoulos, Brown & Wright, 1999) or grounded theory methodologies (for example, Coe & Neufeld, 1999; Crotty, 1998). Other studies (for example, Matthew, Mattocks & Slatt, 1990) employed a
mixed methods approach and included individual interviews, focus group interviews (McFarland & Sanders, 1999) or self-report questionnaires and standardised measures to provide descriptions of males’ experiences. Research methods used included interviews in nine studies (for example, Neufeld & Harrison, 1998) and focus groups in three studies (Neufeld & Harrison, 1998; Coe & Neufeld, 1999; McFarland & Sanders, 1999). Five of the thirteen studies used standardised measures (see Table 3.2). Of interest is the fact that different measures of care giver burden, ADLs and care recipients’ problems were used by researchers although two studies utilised the CES-Depression Scale. Study samples were mostly non-randomised and derived from various sources including snowballing technique, aged care services, death certificates, and existing information from other surveys.
Table 3.2
Standardised Measures Utilised by Researchers to Study Male Carers’ Experiences in Category One Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Measures</th>
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<tbody>
<tr>
<td>Kaye &amp; Applegate (1990b.)</td>
<td>• Zarit, Reever and Bach-Peterson Burden Index (Zarit, Reeves &amp; Bach-Peterson, 1980)</td>
</tr>
<tr>
<td></td>
<td>• Bem’s Sex Role Inventory (Bem, 1974)</td>
</tr>
<tr>
<td>Mathew et al. (1990)</td>
<td>• Zarit Burden Index (Zarit, Reeves &amp; Bach-Peterson, 1980)</td>
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<tr>
<td></td>
<td>• ADL Scale (Moore, Bobula, Short &amp; Mischel, 1983)</td>
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<tr>
<td></td>
<td>• Functional Dementia Rating Scale (Moore, Bobula, Short &amp; Mischel, 1983)</td>
</tr>
<tr>
<td>Miller &amp; Cafasso (1992)</td>
<td>• Zarit Burden Scale (Zarit, Todd &amp; Zarit, 1986)</td>
</tr>
<tr>
<td>Kramer (1997)</td>
<td>• Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, Maiuro, 1991)</td>
</tr>
<tr>
<td></td>
<td>• Memory &amp; Behaviour Problems Checklist (Zarit &amp; Zarit, 1987)</td>
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<tr>
<td></td>
<td>• Ways of Coping Checklist (Vitaliano, Russo, Carr, Maiuro &amp; Becker, Maiuro, 1985)</td>
</tr>
<tr>
<td>Kramer &amp; Lambert (1999)</td>
<td>• Center for Epidemiological Studies – Depression (CES-Depression Scale) (Radloff, 1977)</td>
</tr>
<tr>
<td>Kramer (2000)</td>
<td></td>
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<td>---------------</td>
<td></td>
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<tr>
<td>• Katz Index of ADLs (Katz, 1983)</td>
<td></td>
</tr>
<tr>
<td>• Instrumental ADLs (Katz, 1983)</td>
<td></td>
</tr>
<tr>
<td>• Memory &amp; Behaviour Problems Checklist (Zarit &amp; Zarit, 1987)</td>
<td></td>
</tr>
<tr>
<td>• CES-Depression Scale (Radloff, 1977)</td>
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</tbody>
</table>

There were a small number of participants (25 male carers or less) in ten studies. Eight studies focussed on older male husbands’ experiences, and the remainder focussed on older husbands’ and others’ (for example, sons, grandson) experiences. Male carers’ ages ranged from 51 to 93 years in those studies that focussed on husbands’ experiences. Wives who were being cared for were suffering from dementia or some other form of cognitive impairment in eight of the studies, and other conditions (for example, medical conditions, mental illness) in the remaining studies. Siriopoulos et al. (1999) described the experiences of both husbands providing care for wives at home as well as two husbands who cared for wives in an institutional setting.

Studies sought to examine specific aspects of care giving, for example, the relationship between gender and stress (Kaye & Applegate, 1990c.), individual predictors of strain and gain (Kramer, 1997), the effect of reciprocity on care giving experiences (Neufeld & Harrison, 1998), and the effects of care giving on
household tasks, social integration, marital relationships, and sense of carer wellbeing (Kramer & Lambert, 1999).

Specifically, the review focuses on those studies that have investigated or highlighted older males’ experiences associated with providing care for family members with dementia at home as this was the focus of the present writer’s interest. The researcher had a particular interest to identify those variables that predicted male carers’ burden and depression. A review of male carers’ studies is organised under several headings as follows.

3.2.1 What is it Like for a Male to be a Carer?

Several studies provided a description of what it was like for males to provide care for a family member. The aim of Harris’s study (reported on two occasions in two journals in 1993 and 1995) was to gain insight into the world of the male carer. The study group was a non-random but purposeful sample of 15 male carers who attended Alzheimer’s Association support groups in the U.S. and were providing care for their wives at home, or had just placed them in a nursing home. Wives were at various stages of Alzheimer’s disease. Data were collected through in-depth interviews. The interview schedule included a question about stress or burden associated with care giving. Through thematic analysis of the data, four types of male carers were identified: (1) Worker, who followed a schedule, was highly organised, and modelled their role after their world of work; (2) Labour of
Love carer, who had found a purpose in care giving and provided care out of a sense of devotion; (3) Sense of Duty carer who perceived care giving as a payback for care received from wives throughout the marriage; and (4) Cross-Roads carer, whose experience was characterised by crises, frustration, and stress.

Husbands generally reported feeling sad and disappointed that wives had developed Alzheimer’s disease. “At the Cross-Roads” carers identified that they were often in crisis being new to the role and where wives were in the early stages of the illness. It is possible that this was related to not having had time to become oriented to the care giving role at the time they were interviewed. Interestingly, and perhaps unexpectedly, those men who had been caring longer reported the least burden. One possible interpretation of this finding is that husbands adapted to the role over time. The researchers reported that husbands’ main concern was the loss of control over their own lives.

The researchers proposed that studies of males’ unique care giving differences and the resultant information would assist health and other services to provide appropriate services for men. However, they didn’t compare men and women’s care giving experiences, therefore, it is unclear on what basis they made these claims. In addition, in relation to the types of male carers, we do not know from the study if the four types are static or dynamic or whether male carers go through different stages over time. Also, it is unclear what part other variables played, for example, ethnicity or social class, in the development of male carer types.
Parsons (1997), a Canadian researcher, was also interested to explore the experiences of male carers using phenomenology although the type of phenomenological perspective employed was not articulated. Participants were volunteers who were interviewed at two to three month intervals and were providing care for spouses or parents who had been diagnosed with Alzheimer’s disease with some living in the same households as the sufferer. Findings indicated that carers viewed their role as frustrating and a source of considerable anxiety. They reported feelings of loss, aloneness and loneliness, and identified that they were grieving for their loved ones. From the data the following themes were identified by Parsons: enduring, vigilance, sense of loss, aloneness, loneliness, taking away, searching to discover, need for assistance, and reciprocity. Carers reported that they endured physical demands associated with care giving and also psychological feelings of “doom” and “gloom” (p.396). Care giving was also perceived as a frustrating and anxiety producing experience. Vigilance, or watching out for the person being cared for, was also a source of stress. Aloneness and loneliness highlighted the fact that often the carer stood alone in the role and missed the sufferers’ companionship and friendship. Taking away the sufferers’ decision making opportunities and, therefore, independence, also caused stress. Searching to discover the meaning of behaviour and how to handle it, and to discover the cause or reason for the care recipients’ illness was often time consuming for the carer and a source of frustration. Against these negative consequences, carers highlighted the benefits derived from community nurses’ visits, support groups, family members and neighbours. Whilst some
participants may have felt that providing care offered its own source of
gratification, often it involved a complete role reversal and assumption of total
responsibility for care.

Generalisability of these study findings to older male husbands is restricted by the
type of study, the grouping of male carers’ experiences together so that it is
unclear if older males’ experiences were the same as those of other males (for
example, husbands, sons) or different, and if so in what ways. Moreover, we do
not know if the experiences of those living in the same household were different
in any ways compared to those of the carer who lived away.

Canadian researchers, Neufeld & Harrison (1998), explored the effects of
reciprocity in relationships on carers’ sense of wellbeing. This represented an
attempt by researchers to identify possible causes of changes in wellbeing in
carers. Reciprocity was defined by the researchers as the “bidirectional exchange
of resources” (p. 959) with family and friends and within the care giving
relationship. Their sample size of 22 comprised husbands, sons, sons-in-law, a
grandson, and a brother, who were recruited from multiple sources and
participated in three focus group discussions over an 18 month period. Carers
were providing care for a family member in hospital, long-term care, or at home
who had developed dementia or an unknown cognitive impairment. Grounded
theory techniques were used to analyse the data. The study found that when
reciprocity was absent, for example, where the person receiving care couldn’t
communicate because of the effects of the illness, carers described providing care on the basis of obligation with associated mixed or negative feelings about the role. Obligation referred to feelings, for example, that carers had to return favours toward wives who had provided for their needs during their married life. This was reportedly associated with burden, stress, anger, feeling alone, frustration and depression. Additionally, men were reluctant to accept help. To overcome these consequences, the researchers proposed, that male carers redefined their relationship with an emphasis on loyalty to the person being cared for.

Limitations to the study findings included that cultural variations in care giving were not examined, and the small sample size was recruited from multiple sources. In addition, the sample of males came from middle class and working class families. Moreover, sufferers included those living in the community as well as long term care so that any impacts care receivers’ location, for example, at home versus elsewhere, had on study findings was unknown. Presumably, those living in long term care would have been at a more advanced stage of the illness and would have been less likely to be able to communicate compared to those still living at home. It is uncertain whether study results would apply uniformly to all types of male carers in the study.

3.2.2 How Male Carers Coped with their Role

From the previous section, there are clear indications that male carers may experience difficulties with the care giving role and that not all males coped with
it well. Other researchers examined this phenomenon as a specific focus of their studies. Canadian researchers, Archer & MacLean (1993), for example, examined individual perceptions of six husbands and three sons who were providing care for chronically ill women experiencing medical conditions, for example, diabetes, and chronic mental illness, in relation to the carer role. Of particular interest were males’ levels of stress. Data were collected through interviews. Findings identified that males experienced emotional satisfaction from care giving. However, many were also feeling burdened and this was related, in particular, to changes in husband-wife relationships. Moreover, the researchers also found that maintaining outside interests helped carers to deal with care giving better. All husbands agreed that respite services would conserve their strength, and support services should be sensitive to their needs. However, the extent to which carers utilised respite services and how support services met their needs was not reported.

Findings should be interpreted conservatively because of the small sample size and the fact that carers volunteered to take part from support groups and were therefore perhaps more vocal and motivated or encouraged to lobby to have their needs met. The finding that time out and specific service provision enhanced husbands’ ability to cope appears to be the most important finding.

Elsewhere, U.S. researchers, McFarland & Sanders (1999) studied male carers’ experiences and identified that the most common theme for coping with the
progression of their wives’ disease was maintaining control. This included keeping a journal about wife’s care needs and looking at care giving as an extension of a previous work role. Interestingly, the participants had all made financial and legal plans soon after the diagnosis had been made and this suggested to the researchers that making plans also gave them a sense of control over the situation that they found themselves in. However, study findings should be interpreted carefully as the focus group interview was conducted with an unspecified number of male carers and included husbands, sons, and son-in-laws. The experiences of older husbands were not described but were summed with those of other male carers.

3. 2. 3 Consequences Associated with Providing Care

Several Category One studies demonstrated that male care giving resulted in negative consequences although in some studies it was associated with positive ones (as described in Chapter Two). The following provides a critique of the literature in relation to studies that were specifically designed to identify consequences associated with care giving.

U.S. researchers, Mathew et al. (1990) found that the effects of care giving on males providing care for a family member with dementia, included significant increases in household responsibilities, decreased sense of social integration, marital problems, and a decreased sense of wellbeing for those husbands
providing care at home (n=12) compared to those who had placed their relative in a nursing home (n=8). Using the Zarit Burden Index (Zarit, Reever & Bach-Peterson, 1980), the researchers reported that both groups fell into the mild to moderate burden category. This was perhaps a surprising finding, especially for those men who had placed their relative in a nursing home and could have been expected, therefore, to feel less burdened. Perhaps they continued to visit and do things for their relatives, or felt guilty about placing them in an institution, or experienced anxiety about the standard of care that they observed. It is also possible that these men were grieving for their life’s partner who was deteriorating further. This finding could provide an interesting focus for further research. Generally, men found it difficult to acknowledge stress levels. Against this finding, males providing ongoing care at home reported strong feelings of responsibility for care related to love for the person and a sense of obligation.

Generalisability of study findings may be affected by small participant numbers who were enlisted from multiple sources. For the purposes of the present study, not all carers were husbands so that it is unclear what husbands’ unique experiences were. Moreover, husbands were providing care for various family members so that it is unclear whether there were any differences in carers’ experiences associated with caring for wives compared to those providing care for other family members. It is also unclear what factors were causing husbands who were providing care at home for wives with dementia to feel burdened.
U.S. researchers, Kaye & Applegate (1990b.) reported that many men in their study were providing care and experiencing significant levels of stress. What intrigued them was the possibility that male carers might experience less burden or stress associated with care giving with the freeing up of sex role conceptions. Male carers were mostly older husbands caring for wives who had developed Alzheimer’s disease or a related disorder. Data were collected from surveys completed by 148 men who were attending support groups and used various measures (see Table 3.2). Interestingly, it was found that the men in this sample who described themselves to a greater degree in affective terms - loving, gentle, compassionate - experienced lower burden levels than those who described themselves in instrumental terms - self-sufficient, analytical, competitive. However, as subjects were enlisted into the study from support groups, one possible interpretation of the findings is that older males with more affective qualities were more likely to attend groups. It is unknown, therefore, whether older males who take on the carer role are generally more affective compared to those who place their wives in a nursing home earlier in their illness.

The purpose of Kramer’s (1997) study was to identify predictors of strain and gain among husbands of wives with dementia in a U.S. context. The researcher found that strain, as measured by a 25-item Screen for Caregiver Burden which the researchers developed, was associated with sufferers’ memory and behaviour problems, length of time providing care, use of emotion-focussed coping strategies, for example, those characterised by emotional responses such as
frustration, anger, personal resources of the care giver and carers’ poorer health. What made this study somewhat more interesting was the researcher’s interest in what benefits males derived from the care giving role and this was referred to as gain, or the extent to which the role was viewed as enhancing the carer’s life in some positive way. Parsons (1997) and Archer & McLean (1993) reported a similar finding relating that some male carers found the role to be a source of considerable emotional satisfaction. Predictors of gain for husbands in Kramer’s study included that they were less educated, satisfied with social circumstances, were in better health, and made greater use of problem-solving coping strategies. Most of the findings were not difficult to understand but less education probably needs some explanation. The author suggested that carers with better education perceived care giving as demonstrating a greater differential status compared to their previous professional roles, and this was not such a problem, therefore, for those with less education. Limitations associated with interpreting study findings included the cross-sectional nature of the study, the non-representativeness of the sample and preponderance of Caucasian men who tended to have at least some high school education. As the study was cross-sectional in design rather than longitudinal, we do not know whether husbands would continue to experience a sense of gain over time as wives’ disease progressed and carers were required to provide increasing supervision. Another interpretation of findings is that men were not always able to disclose the sense of burden and even depression that they were experiencing (see also Kramer & Lambert, 1999; Matthew et al., 1990).
Kramer & Lambert (1999) examined the effects of care giving on the amount of time husbands spent in household tasks, social integration, marital relationship and sense of wellbeing. The study was a two group comparative design study in which group one husbands’ (aged over 60 years of age) were compared with a non-care giving control group of husbands and healthy wives. Group one wives were experiencing various illnesses and disabilities. There were 288 participants in the study who were randomly sampled from data from a national survey of carers in the U.S. Data were collected through interviews, self-administered questionnaire, and two quantitative measures (see Table 3.2). Data about number of hours spent weekly on care giving tasks, social activities, and marital happiness were also obtained. Generally, the researchers found that husbands were experiencing a reduced sense of psychological wellbeing among those providing care. Specifically, they were becoming less happy and increasingly depressed compared to husbands with well spouses. Findings also indicated that group one husbands experienced significant changes in household responsibilities (both amount and type), a decreased sense of social integration, and relationship problems. However, the researchers did not examine what the social and relationship changes were related to.

Canadian researchers, Siriopoulos et al. (1999) encouraged husbands to tell their stories and articulate their experiences associated with care giving. Participants were eight husbands of wives with dementia. Six of these carers were providing care at home and two had been ‘providing care’ for wives in a nursing home.
Whilst the researchers stated that the nursing home husband-carers had no trouble providing a description of their previous care giving experiences (whilst at home), three years had gone by and they may have not been able to accurately remember their previous experiences while providing care at home. Additionally, all participants were white, Anglo-Saxon Protestants with a wide range of educational backgrounds. These participant characteristics and their small number limit the generalisability of study results to male carers more generally.

Study findings, however, were quite interesting and included the negative impact on what had previously been a good relationship, caregiving motivated by a sense of obligation to care for wives as wives had cared for them, and love associated with their marriage vows. Losses related to their wives’ illness were also highlighted as well as difficulties accepting their wives’ diagnosis. A sense of loneliness was also reported. Another theme was ‘missing the way she was’ so that the carer was no longer able to share thoughts and feelings with them.

Stressors identified, causing a sense of burden, included wives’ disruptive behaviour, feeling tied down, unfamiliar role demands, constant supervision, and wives’ memory problems. Husbands frequently felt angry and frustrated. Coping strategies included day care utilisation, assistance from family and friends, humour, establishing a routine, holding on to memories, letting go, and trying to let their wives do as much as possible.

Elsewhere, Kramer (2000) examined patterns of change over time for 74 husbands who continued to care for spouses and the effects of this on their experiences of
burden and depression. The study was a two group design comparing the experiences of husbands who were caring for spouses at home, and those who were providing care for wives in nursing homes in a U.S. context. Study subjects were recruited from multiple sources and interviewed on two occasions over a one year period. Several measures (see Table 3.2) were used to examine their experiences, including CES-Depression Scale to identify individuals at risk of depression. In addition, data were collected about husbands’ self rating of their own physical health and satisfaction with social participation. In this study, all wives were suffering from dementia. Findings indicated that group one husbands who expressed satisfaction with health and social activity levels, reported lower levels of depression and stress. One possible explanation for this is that they had adapted to the role over time. Group two husbands reported that their health had improved and that they were less stressed after placing wives in a nursing home, a not unexpected finding. However, the writer suggested that there were no changes in their level of depression, and the researchers highlighted that this may have been related to the grieving process that had become more pronounced as sufferers moved on to the next stage of their disease. Moreover, a similar finding was reported by Matthew et al. (1990) earlier in this section, that husbands who had placed wives in a nursing home still continued to feel burdened.

Limitations to the generalisability of study findings included the cross-sectional nature of the study and non-representativeness of the sample. Moreover, group members were Caucasian and had at least a high school education and incomes
above the poverty line. Sample numbers may have limited the power to detect differences between groups. Additionally, we do not know if the same results would be obtained for group one carers if sufferers had been more restricted in Activities of Daily Living (ADLs) than they were.

Several studies focussed on the supports that were available to husband-carers and the extent to which they were utilised by them.

3. 3 Supports for Male Carers

A short journal authored by U.S. researcher Vinick (1984) reported that older husbands in his study, who had previously been providing care for spouses who were disabled with various conditions, assumed primary responsibility for their wives but received considerable help from nurses, in particular, but not from others. However, the types of help received from nurses were not described nor evaluated. Limitations associated with the study were related to the small sample size (n=25) and failure to identify how the sample was derived. Additionally, widowers, who were interviewed, had ceased providing care from between two and a half to three years. This may have affected their memory of care giving experiences and feelings associated with the role.

An exploration of 24 male carers’ experiences was undertaken by Canadian researchers Coe & Neufeld (1999). Subjects were volunteers who took part in
two to three guided focus group interviews over 18 months. Data were derived from secondary analysis of interview data using grounded theory. Carers were mainly husbands and 29% of the participants were over 60 years of age. Those receiving care were cognitively impaired wives, sons, a brother, son-in-law, a grandson, and a friend. The carers reported negative feelings about their experiences, including being frustrated, feeling helpless, uncertain and desperate. Feelings were highlighted more when care giving responsibilities became too intense for the carers and exceeded their emotional and physical abilities.

Findings indicated that there were four stages of care: resisting (in which they did not seek help); giving in (that is, requesting support; opening the door (although ready to accept help, barriers were encountered including lack of information and not knowing where to go for help), and finally, making the match (between their own needs and the needs of care receivers). However, we do not know if all male carers go through these stages and ‘make the match’. Limitations associated with study findings included the small sample size, various males (eg. older men, sons) being included in the analysis so that the unique experiences of each group of male carers were not identified.

McFarland & Sanders (1999) reported that men had difficulty accepting outside services and in particular those that could assist with the care giving role. This was seen by the men as an admission of weakness or failure on their part and that they weren’t managing. Typically, a female relative or trusted professional convinced them to utilise outside support services.
3.4 Conclusions

Researchers utilised qualitative or quantitative research paradigms or a mixed methods approach, to examine males’ experiences of care giving. From the literature review, researchers were interested to describe what it was like to be a male who was providing care for a family member. A number of studies either investigated or reported that there were various psychological consequences associated with caring and these were variously described as burden, stress, considerable anxiety, frustration, and strain. Questions about carer stress or burden were asked as part of an interview schedule, or descriptions of psychological consequences associated with care giving arose out of an analysis of interview data. Several studies utilised standardised burden measures to investigate carers’ burden levels. However, different measures of burden were used in three of the studies reviewed (Kaye & Applegate, 1990b.; Mathew et al, 1990; Kramer, 1997). This highlights that it is difficult to compare burden levels of male carers across studies as different measures may have been measuring very different phenomena.

Several studies identified factors that contributed to carers’ sense of burden whilst others identified that males were burdened, but didn’t examine what the causative factors were. From a review of Category One studies, burden was related to carers’ behaviour, characteristics of the carer role and the carer, changes in the
relationship, lack of understanding of the causes of the illness and behaviour, feeling tied down, unfamiliar role demands, and carers’ memory problems.

Characteristics of the Care receivers’ Behaviour

Burden and stress were associated with wives’ severely disturbed behaviour (Parsons, 1997; Siriopoulos et al., 1999), memory loss (Parsons, 1997; Kramer & Lambert, 1999; Siriopoulos et al., 1999), cognitive impairment, communication difficulties (Parsons, 1997).

Characteristics of the Care giver Role

Burden was associated with a range of characteristics including physical demands of the role (Parsons, 1997; Siriopoulos et al., 1999), being constantly vigilant, (Parsons, 1997), being tied down (Siriopoulos et al., 1999), making decisions on behalf of wives, role reversal and unfamiliar role demands (McFarland & Sanders, 1999; Siriopoulos et al., 1999), and total responsibility for care (Parsons, 1997), amount of time taken up with providing care and increased household responsibilities (amount and type) (Kramer & Lambert, 1999). Care giving responsibilities often resulted in disruptions to the carers’ personal life affecting it negatively in various ways (Harris, 1993, 1995). Care giving based on a sense of obligation and duty caused mixed or negative feelings about the care giver role (Neufeld & Harrison, 1998). Loss of friends resulted in feelings of anger and
anxiety (Neufeld & Harrison, 1998). Care giving had resulted in loss of friends (Neufeld & Harrison, 1998) and a decreased sense of social integration (Kramer & Lambert, 1999) which in turn was associated with decreased psychological wellbeing.

**Characteristics of the Care giver**

Husbands who were reluctant to accept help (Neufeld & Harrison, 1998) were described as feeling burdened, stressed, angry, frustrated, and alone (Neufeld & Harrison, 1998). Some male carers found it difficult to acknowledge stress (Matthew et al., 1990) and those who used more emotion-focused coping strategies, had less personal resources, were experiencing poorer health, and reported greater strain (Kramer, 1997). More negative feelings towards care giving occurred when carers’ responsibilities became too intense and exceeded their emotional abilities (Coe & Neufeld, 1999).

**Changes in the Relationship**

Male carers experienced burden and stress where the illness resulted in lost companionship and friendship (Parsons, 1997) and anticipation of loss (Siriopoulos et al., 1999), where marital problems resulted from communication problems (for example, Kramer & Lambert, 1999) producing a sense of loss for the person they once knew (Parsons, 1997). Burden was also experienced where
the carer had to make decisions on behalf of their spouse as this was perceived as taking away their spouse’s independence (Parsons, 1997).

To summarise the category one studies, less burden or strain was associated with more affective traits (Kaye & Applegate, 1990b); using problem-solving coping strategies (Kramer & Lambert, 1999); being in better health, being satisfied with their social circumstances and level of social activity; getting something out of care giving; less education and satisfaction with social circumstances (Kramer, 1997). Those reporting better health (Kramer & Lambert, 1999) and being emotionally satisfied with the care giving role (Archer & MacLean, 1993) also reported less burden or stress.

Few studies examined whether male carers were experiencing depression. Where it was reported several terms were used to describe the phenomenon, including depression, feelings of gloom and doom, sense of loss and decreased feelings of happiness. It is unclear whether carers studied were experiencing depressive symptoms or were clinically depressed. Only two studies utilised a depression scale (CES-Depression Scale) so that we have little information about depression in male carers generally and older male carers in particular. Where it was reported, it was related to a decreased sense of social integration (Kramer & Lambert, 1999) and grieving (Kramer 1997; 2000). Lower levels of depression were found to be associated with males’ satisfaction with health and their social activity levels (Kramer, 2000).
Attention now turns to Category Two studies designed to compare the experiences of male and female carers.

3. 5 Category Two Studies

Study samples in Category Two studies were derived from multiple sources (for example, Miller, 1987) including: sub-samples from a larger sample (for example, Almberg, Jansson, Grafstrom & Winblad, 1998), a list of psychiatric service clients (for example, Collins & Jones, 1995), clients of a research centre (for example, Rose-Rego et al., 1998), and various clinical settings (for example, Croog, Sudilovsky, Burleson & Baume, 2001). Study methods included structured questionnaires (for example, Borden & Berlin, 1990), surveys (for example, Gallichio et al., 2002) and interviews (for example, Miller, 1990). A variety of measures were used in the studies reviewed and these are identified in Table 3.3. From the table, the only standardised measure used by more than one researcher was the CES-Depression Scale. Other assessments included health and behaviour of carer (for example, Miller, 1987), use of psychotropic drugs (Miller, 1987), overall physical health (for example, Rose-Rego et al., 1998), emotional health and social functioning (for example, Rose-Rego et al., 1998), and self-rating of physical health (for example, Gallichio et al., 2002). Studies ranged from small (n=24) to large (n=259) sample numbers. Samples included older husbands (for example, Collins & Jones, 1995), older wives (for example, Croog et al., 2001), siblings, adult children, distant relatives, friends and neighbours.
Family members receiving care had been diagnosed with Alzheimer’s disease or a related disorder (for example, Croog et al., 2001), cognitive impairment (Miller, 1990), chronic dementia (Borden & Berlin, 1990), and dementia (for example, Collins & Jones, 1995).

An additional article, by Miller & Cafasso (1992), described a meta-analysis of 14 descriptive studies of gender differences in care giving and is described on page 102.

**Table 3.3**

**Standardised Measures Utilised in Category Two Care giver Studies**

<table>
<thead>
<tr>
<th>Study</th>
<th>Standardised measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borden &amp; Berlin (1990)</td>
<td>• Ways of Coping Checklist (Vitaliano, Russo, Carr, Maiuro &amp; Becker, Maiuro, 1985)</td>
</tr>
<tr>
<td></td>
<td>• Mental Health Index (Williams, Ware &amp; Donald, 1981)</td>
</tr>
<tr>
<td>Collins &amp; Jones (1995)</td>
<td>• General Health Questionnaire (Goldberg &amp; Hillier, 1979)</td>
</tr>
<tr>
<td></td>
<td>• Life Satisfaction Scale (Diener, Emmons, Larsen &amp; Griffin, 1985)</td>
</tr>
<tr>
<td></td>
<td>• Problem Behavior Checklist (Hughes, Berg &amp; Danziger, 1982)</td>
</tr>
<tr>
<td>Almberg et al. (1998)</td>
<td>• Burden Questionnaire (Grafstrom, Fratiglioni, Sandman &amp; Winlad, 1992)</td>
</tr>
<tr>
<td>Rose-Rego et al. (1998)</td>
<td>• CES-Depression Scale (Radloff, 1977)</td>
</tr>
</tbody>
</table>
From the literature review, nine Category Two research studies were identified which focussed on the similarities and differences between male and female carers’ experiences in relation to burden and depression. Of these five were U.S. studies, and one each from Canada, Denmark, and the UK.

These will now be reviewed in the light of the present writer’s interest in care givers’ experiences of burden and depression, particularly where these phenomena occur in older male carers. Studies used various terms to describe the consequences associated with care giving including emotional distress (for example, Rose-Rego et al., 1998), anxiety (for example, Croog et al., 2001); depression (for example, Gallichio et al., 2002), strain (for example, Almberg et al., 1998), tension (for example, Borden & Berlin, 1990), psychological distress (for example, Borden & Berlin, 1990), burden (for example, Collins & Jones, 1995), psychological morbidity (for example, Collins & Jones, 1995), and impaired well being (for example, Croog et al., 2001). The use of various terms by different researchers makes it very difficult to evaluate whether the researchers were reporting the same phenomenon. Nevertheless, there is good evidence to suggest that providing care places various strains on the carer and results in psychological and even physical consequences.
Stresses and Strains

There are indications in the literature highlighting how being in charge of another person caused difficulties for female carers in particular. This phenomenon was identified earlier by Miller (1987) who explored the perceptions of spouses caring for cognitively impaired partners. The sample was derived from participants in a small respite program for persons with memory loss. Structured questionnaires and semi-structured interviews were used to capture their perceptions, as well as the Zarit Memory and Behaviour Checklist. In addition, information was collected about carers’ health and behaviour and use of psychotropic drugs. Spouses receiving care had been diagnosed with Alzheimer’s disease or a related disorder (for example, multi-infarct dementia, Parkinson’s disease, and severe depression). Female carers experienced problems with control of another person, gave greater attention to interpersonal relationships and gave the impression of experiencing less emotional stress, but experienced occasional periods of depression. For males, being in charge of another person (their wives) was seen as being an extension of the role of authority figure and resulted in less stress and strain for them. In addition, male carers under-reported symptoms, not acknowledging as many signs of depression, anxiety, emotional stress, and demoralisation as female spouse carers did. One possible explanation for this finding is that males may not have been able to discuss how they were feeling about the role with the researchers. Male carers were also less likely to attend support groups but the reasons for this were not explored. It could have been, for
example, that the groups were not perceived by them to be able to meet their particular needs. The researcher acknowledged that the findings of the study were exploratory. It is worth highlighting that the participants were from an upper middle-class white suburban population and were attending a respite programme. Miller’s (1990) research focussed on whether there were any differences between the stresses and strains experienced by male and female carers. There were 554 participants in the study, derived from a sub-sample of spouse caregivers of the National Long Term Care Survey. Carers included 203 husbands and 351 wives of non-institutionalised persons 65 years of age and over who received assistance with ADLs. Care recipients had some cognitive impairment or were described as ‘senile’ (p.314). Presumably this means that they had developed a dementing illness. The researchers investigated care strains which they defined as “subjective perceptions of behaviour and personal limitations that may accompany care giving” (p.315). From the data, three types of strain were identified: Time strain – where taking care of spouse limited the carers’ social life; Health strain – where the carer had to provide almost constant attention to the care receiver, and Emotional strain, where providing care had caused the carers’ health to deteriorate. Husband and wife carers showed a small difference in health strain with wives reporting significantly more health strain as a result of care giving. In addition, wives showed a tendency toward greater time strain. The level of use of non-marital (other than each other) ADL and other support was low for both male and female carers. However, male carers were more likely to report that impaired
wives helped with household chores. It is unclear if this reduced males’ sense of strain.

Study limitations included that the sample was mainly Caucasian and a large number lived in urban areas. Moreover, wives, compared to husbands, were more likely to be caring for cognitively impaired husbands, it is perhaps not surprising, therefore, that they experienced higher burden levels. Types of strain identified here may not be the same in other studies. Additionally, the contribution of both social role and gender socialisation perspectives in relation to males’ and females’ experiences of care giving was not examined.

Borden & Berlin (1990) were not only interested in studying carers’ wellbeing but also the effects of carers’ gender types and coping strategies and their impact on their sense of wellbeing. Sixty-one participants were derived from a sub-sample of spouses from the National Long Term Care Survey Caring for Older Adults and comprised spouses (59% of whom were women and 41% men), caring for older adults with chronic dementia of at least one years duration, its severity being assessed by the Memory and Behaviour Problems Checklist. Data were collected through self-report questionnaires and semi-structured interviews. In addition, carers were asked to complete the Ways of Coping Checklist, and Mental Health Index.
Findings indicated that men and women used problem-solving strategies with equal frequency, however, female carers placed greater reliance on tension reduction activities, for example, over-eating to feel better, drinking, smoking, drugs, and support seeking, for example, talking to someone about feelings. Positive appraisals (for example, ‘Looking on the bright side’) of their circumstances by both male and female carers were more likely to lead to higher levels of wellbeing. Carers, of either sex, who were “Trying to make sense” (p.607) of the illness by relying on religious or philosophical beliefs were viewed by the researchers as developing a sense of purpose and meaning in the midst of ‘chaos’ and loss. Reliance on wishful thinking (for example, “hoped a miracle would happen”) was associated with lower levels of wellbeing. Men reported lower levels of psychological distress than women carers. It is not possible to identify why this was so as it wasn’t investigated or commented upon by the researchers. As this was a cross-sectional study it is uncertain if positive coping strategies continued to be effective as the illness progressed and as care giving became more difficult.

Miller & Cafasso’s (1992) article, referred to earlier, was a meta-analysis of 14 descriptive studies of gender differences in relation to family care giving. Findings indicated that there were no significant gender differences in caregiving stressors and burden, functional impairment of the frail care recipient, total care giver involvement in care, or in money management tasks. It was highlighted, however, that female care givers were more likely to carry out personal care and
household tasks and more likely to report more burden. However, the effect size was small and the authors highlighted the need for researchers to examine the part that gender-role explanations play in assigning meaning to care giving behaviours.

Almberg et al. (1998) referred to the psychological impact of care giving on carers as carer strain and their study explored the differences between and within genders in relation to this phenomenon. Their sample of 52 carers of demented elderly relatives and 66 carers of non-demented elderly relatives, was identified from a population based longitudinal study by the Stockholm Gerontological Research Centre, Denmark. Data were collected using interviews and a burden questionnaire. Carers were spouses, siblings, adult children, distant relatives, friends and neighbours. Carers of demented elderly relatives consisted of 37 females and 15 males (non-demented participants comprised 43 females and 23 males). Of the demented elderly care receivers, 15 lived at home and seven had been institutionalised. Of those who were non-demented, 61 lived at home and five had been institutionalised. Findings included that there were no significant differences between carers for demented and non-demented carers on the burden measure. However, females caring for demented elderly suffered the most strain and carers of demented elderly, did not view the role positively, receiving limited social support. Carers of demented elderly people generally and women in particular, reported more conflicts with their family members. However, the researchers did not elaborate on what these conflicts were nor why they occurred. Males caring for a demented elderly relative reported a more negative outlook and
a greater need for social support. Limitations to study findings included lack of information about how the sample was formed, size of the groups when the population was differentiated into sub-groups, and the number of drop-outs (n=11) caused by a high death rate for the very old subjects in the study.

In the U.K., researchers Collins & Jones (1995) examined if female carers for demented dependents experienced more emotional distress and psychiatric morbidity than men and sought to clarify what factors might account for any differences that might be found. The sample comprised two matched groups of spouse carers for dementia sufferers (male and female, 24 in each group). The gender groups were matched for age, social class, length of relationship and time care giving, dependent person’s age, diagnosis, and severity of dementia. The sample was assembled from all spouse carers of demented patients in contact with the psychiatric service of the Department of Health, University of Nottingham. Data collection methods are identified in Table 3.3. In addition, amount of time performing personal care and housework, a specially designed schedule to record ‘objective’ burden, a measure of the practical impact of care giving on subjects’ lifestyles, and an interviewer assisted questionnaire, were also used. Findings for wives in contrast to husbands indicated that emotional stress and psychiatric morbidity was significantly greater for female carers. The researchers also found that male carers received more formal support, were more positive about the relationship, and more involved in management tasks. Both males and females viewed females as generally better suited to the care giving role. Limitations to
study findings included that multiple statistical comparisons with a small sample may have led to type one errors when significant levels were set at .05.

U.S. researchers, Rose-Rego et al’s. (1998) study of carers was based on a two-group design study that examined the differences in subjective psychological wellbeing between husband and wife carers of persons with Alzheimer’s disease compared to non-carers of well elderly spouses. They were also interested in the type of coping strategies utilised. Participants were enlisted from the caregiver population database of the Alzheimer’s Disease Research Centre and completed a series of questionnaires. These enquired about carers’ emotional health, social functioning and ties, satisfaction with social activities, sense of mastery, overall physical health, and global life satisfaction. Measures used were Satisfaction with Life Scale and the CES-Depression Scale. The study was a two group design comprising 99 spouses (average age of 70 years) living with someone with dementia, and 113 spouses living with a healthy spouse. Findings indicated that husbands and wives used the same type of coping strategies, but wives experienced more stress associated with care giving and negative psychological states, including depression. Psychological consequences were significantly different between husband and wife carers and the comparison group of husbands and wives with the former experiencing more negative feelings about the care giver role.
Limitations to study findings included that the sample was pre-dominantly Euro-American. In addition, duration and specific activities associated with caring were not examined in the study nor were relations between wellbeing and the cognitive and functional capacities of the care receivers. Data from each person in a married couple will not, however, be truly independent of the influences marriage has on each other’s responses and each other’s responses, therefore may be influenced by the other partner.

Other studies also examined the relationship between numerous variables and subsequent effects on carers’ emotional wellbeing. For example, Croog et al. (2001), U.S. researchers, explored the relationships between problem behaviours and vulnerability factors in wellbeing and emotional health of their spouses. Data were collected from 11 clinical settings involved in drug trials, and interviews conducted by nurses, social workers and graduate students in psychology. Measures used in the study were Total Patient Care, Patient Problems, and Clinical Assessment Scales, carer self-ratings, wellbeing and health, and emotional state. Of the 199 carer participants, 80 were male and 119 female who were aged between 50 and 80 years of age and caring for wives and husbands with Alzheimer’s disease, living in the community. Spouses were aged between 46 and 82 years with a mean age for husband carers of 68.4 years and 66.8 years for wives.
Findings indicated that males scored significantly higher on the anxiety scale and reported patient personal care problems more, especially destructive behaviours. Emotional lability, related to care giving, was the strongest predictor of impaired wellbeing for both male and female carers. Both male and female carers were similar in the volume of patient problems they perceived, but their reactions to the problems differed. It could be that male and female carers differed in their perception of the carer role and responded differently to it. Younger, more so than older care givers, appeared more at risk for stressor burden and this is perhaps not surprising. Young carers (husbands) and wives were more similar than older husbands in relation to total patient stressor burden and carer response. Arguably, older carers were not feeling as burdened as their younger counterparts as they had diminished expectations in regard to the health of the relative being cared for, and were more clearly aware that they and their partners were ageing and health problems, therefore, were to be expected.

Limitations of study findings are associated with the fact that 41% of husband-carers and 39% of wife carers were working on a full-time or part-time basis and their experiences of caring, therefore, may have been very different to those carers who had been providing full-time care.

Canadian researchers, Gallichio et al., (2002) labelled the psychological consequences associated with care giving as becoming burdened or depressed and set out to examine any gender differences that might exist in respect of these
phenomena. The sample was identified from the Canadian Study of Health and Aging, and election and municipal records and data were collected through interviews, and completion of Zarit Burden Scale (Zarit, Todd & Zarit, 1986), CES – Depression and Dementia Behaviour Disturbance Scales, self-rating of physical health and functional status of the care giver. Formal service use and demographic data were also recorded. In this study, there were 259 females and 68 males, over 65 years of age. Study findings indicated that female carers had a higher burden score than male carers but not higher levels of depressive symptoms. A high level of care receivers’ behaviour disturbance and poorer carer health was significantly associated with a high score for both male and female carers. Limitations to generalisability of the study findings included: the majority of carers were female, English Canadians, spouses or children of the dementia patient and the majority of carers lived with sufferers but patients did not always have a primary carer. Persons being cared for were spouses, mothers, or fathers. It is difficult to know whether the experiences of both male and female carers are similar or different or if so in what ways.

Mittelman (2003), a US researcher, compared male and female carers’ experiences on several variables. Participants were 244 female and 162 male carers of family members with dementia at home. Carers, on the whole were older than 65 years of age. Between 6.8% of males and 14.3% of females were younger. Older female carers were mostly homemakers but males were either still employed, or retired. The researcher described differences between male and
female carers’ experiences on several variables. Both male and female carers reported taking over the roles of their spouses. Generally, care giving restricted other activities, for example, spending time with friends and family members. Nearly twice as many male carers compared to female carers received assistance from daughters. Possibly, more male carers asked for help or daughters perceived that they needed or expected more assistance than their mothers did. Where carers employed paid help, females and males were found to use it differently. Males were more likely than females to use the paid help to perform tasks traditionally performed by their wives, for example, cooking and housekeeping. Changes to the relationship were also reported including that husbands believed that wives were no longer their spouse, although physically present in the household. Many male carers had become socially isolated not being able to go out because of, or embarrassment over, their wives’ behaviour. Another interpretation is that they no longer received invitations to visit others. Strengths associated with this study included the size of the sample, multiple assessments for each person participating and the low attrition rate.

3.6 Conclusions

In relation to psychological consequences associated with care giving, what picture of older male spouses’ experiences is identifiable from Category Two studies? Firstly, it is evident that different terms were used to describe these phenomena. This fact makes it difficult to identify just what was being measured
by the different researchers. Generally, though it is evident that carers were affected in negative emotional ways, however, researchers did not always investigate what these were related to. Moreover, study results were somewhat contradictory as the following will demonstrate.

Miller & Cafasso’s (1992) meta-analysis of men and women’s care giving experiences identified that there were no significant gender differences in care giving stressors and burden. However, later Croog et al., 2001) highlighted that male carers experienced higher anxiety levels compared to female carers. The writers suggested that men’s anxiety was related to attending to spouses’ personal care. Other studies found that both male and female carers experienced high levels of burden (Gallichio et al. 2002) and depression (for example, Almberg et al., 1998) and males who were caring for a demented elderly spouse, did not view the role positively and received little support. In Gallichio et al’s study high levels of burden and depression for carers were found to be related to the carers’ health status and increases in care receivers’ problem behaviours, however, Miller (1987; 1990) found that male carers reported less anxiety, depression, anxiety and emotional stress compared to female carers. One explanation for this finding is that they were unable to express the emotions that they were feeling to others. Perhaps this is one reason why males in Miller’s study were more involved in managerial tasks (see also Collins & Jones, 1995) as they felt less stressed where they were providing care based on a model they had been more familiar with for most of their working lives.
Borden & Berlin (1990) found that where male and female carers experienced lower levels of depression, this was related to their use of problem-solving strategies, reliance on religious beliefs and looking for a sense of purpose and more positive appraisals of their circumstances (see also Gallichio et al., 2002). This latter finding is consistent with other researchers’ findings (for example, Collins & Jones, 1995) that male carers were more positive in their outlook about the situation they found themselves in.

Category Three studies focussed on carers’ experiences generally, not specifically setting out to compare males’ experiences with females’. However, within the reported findings, some care giving experiences of males were highlighted.

3. 7 Category Three Studies

Category Three studies reviewed indicated that researchers were interested in various aspects of care giving. Studies focussed on psychological and physical consequences associated with care giving; ways in which carers coped with and managed care giving; care giving activities and experiences; and effectiveness of family, group and one to one interventions.

Nine studies focussed on carers’ experiences generally. These were published between 1988 and 2006 and were conducted in the US, in the UK, in Canada, in Sweden and Australia. Research methodologies used were descriptive-surveys
(for example, Brown, Sloman, Brown & Mitchell, 1995; Shua-Haim, Haim, Yong, Kuo & Smith, 2001; Matthews, Dunbar-Jacob, Sereika, Schulz & McDowell, 2004). Study samples were derived from health professionals’ referrals (Anthony-Bergstone, Gatz & Zarit, 1988; Matthew et al., 2004), multiple sources (Barusch, 1988), support groups (for example, Brown et al., 1995; Robinson et al., 2001), a convenience sample from a medical centre (for example, Wright, Lund, Caserta & Pratt, 1987), and several studies were unclear about how the sample was formed (for example, Carmack, 1997; McGarry & Arthur, 2001). Research methods used included questionnaires (Brodaty & Hadzi-Pavlovic, 1990; Brown et al., 1995) and these employed various standardised measures, including Zarit Burden Scale (Zarit et al., 1980), Problem Behavior Checklist (Brodaty & Hadzi-Pavlovic, 1990), Jaloweic Coping Strategies (Jaloweic, Murphy & Powers, 1984), General Health Questionnaire and a Dysfunctional Behavior Rating Inventory (Dicker, Chawla & Preston, 2006).

Study findings will now be examined under two headings: extent of stress experienced and coping strategies, and available supports.

**Extent of Stress Experienced**

Anthony-Bergstone et al. (1988) evaluated the extent to which stress was experienced by carers. A large group of carers (n=184) of dementia patients, all of whom had primary responsibility for the patients, were recruited from a
training programme designed to assist them in their role as carer. To be included in the study, sufferers had to have a mini-Mental State Examination (MMSE) score of less than 20, and a 6 months history of dementia. Participants comprised 45 husbands, 51 wives, 60 daughters, 13 sons, and 15 other relatives. Some carers lived in different households to the sufferers although all sufferers were living in the community. Data were derived from administration of the Brief Symptom Inventory and the Zarit Burden Scale (Zarit et al., 1986).

Study findings suggested that older men were significantly elevated on hostility and anxiety scores compared to women. Hostility included feeling easily annoyed, or irritated, temper outbursts, and getting into frequent arguments with the person being cared for. Measures of depression highlighted higher scores for older female carers. However, causes of hostility, anxiety and depression were not examined by the researchers nor why older men scored higher on measures of hostility and anxiety and women on depression.

Australian researchers, Brodaty & Hadzi-Pavlovic (1990) examined the rate of psychological morbidity and depression among carers of family members and non-carers experiencing dementia from a community-based support group. Participants in the study were asked to complete a self-report questionnaire, and various measures including Zung Depression Scale, Problem Behaviour Checklist (Zarit, Reever & Bach-Peterson, 1980), and Clinical Dementia Rating Scale (Berg, 1988). There were 311 carers in the study, of these 62% were spouses,
31% adult children, 2% siblings, and 4% other. Forty-six percent of group one carers were male. Sufferers were experiencing Alzheimer’s disease or a related disorder.

Findings indicated male and female spouse carers suffered more psychological distress than non-spouses. Interestingly, and similar to other study findings, carer distress decreased with time. Carers reported being isolated and had fewer family members close by and spoke to far fewer people than would be expected in an age-matched group from the general Australian population, suggesting that caring for someone with dementia had an isolating effect. Additionally, satisfaction with marriage had decreased significantly and those carers least satisfied were most distressed. Vulnerable carers were characterised by the concurrence of psychological, physical, and social isolation. An interesting finding was that while carers were psychologically distressed, they were not significantly depressed. One possible interpretation of this finding is that 11 of the 20 Zung Depression Scale items are biological in nature, for example, sleep disturbances, eating disturbances, and that the carers lacked a lot of these features. Interestingly, carers reported no significant physical and social impairments. The researchers suggested that where physical effects associated with care giving were evident they were related to exhaustion. Overall, male carers were experiencing less psychological morbidity than female carers.
Researchers Carlson & Robertson (1990) explored the experiences of spouse carers of elderly dementia patients living in the community and were particularly interested in the types and levels of stress experienced by them. The sample comprised 38 spouse carers of partners with dementia. All were retired, resided in Alberta, Canada, were married to and living with a spouse diagnosed as having dementia and were primary carers on a daily basis. Most of the couples lived in large urban areas. Data were collected through a questionnaire and various measures including the Sickness Impact Profile, Objective Burden Scale, and Subjective Burden Scale. Findings indicated that there was a positive correlation between length of time since diagnosis and objective burden (related to attitudes and emotional reactions towards care giving) levels for male carers. Overall, husband and wife carers reported experiencing similar levels of objective and subjective burden (related to care giver lifestyle and relationship changes). This suggests that they experienced similar changes in their lifestyles and relationships after their partners developed dementia, and similar attitudes and reactions toward the care giving experience. Neither physical nor psychosocial impairments predicted objective or subjective burden for male or female carers in the study. However, the longer the time since diagnosis, the greater the burden experienced by female carers. None of the variables were associated with male objective burden. One possible explanation for this finding is that male lifestyles and relationships may not have been interrupted to the same degree as those of female carers but this hypothesis would need to be tested in future studies.
Limitations to study findings included the cross-sectional design of the study and as care giving is a dynamic process it cannot be completely portrayed using this design. Additionally, generalisability of findings is affected by the non-random selection of the sample and the large number of Caucasian participants.

Neundorfer (1991) set out to examine carers’ appraisal of stressfulness related to patients’ problems, carers’ appraisal of their options for managing the care giving situation, and the coping strategies used. The sample was recruited primarily from a research registry of an Alzheimer’s Centre of a mid-western university hospital in the U.S., adult day care centres, community offices of ageing, carer support groups and churches. Data were collected through various measures including Memory and Behaviour Checklist, Ways of Coping Checklist, and Physical Health Section of OARS. Sixty carers, (63% wives and 37% husbands) took part in the study. Carers had a mean age of 72 years. All sufferers had been diagnosed with dementia. Findings indicated that there were no significant differences between husbands and wives on carer stress, appraisal of the care giving situation, coping, depression and anxiety. Moreover, husbands had significantly better physical health than wives. It is unknown, therefore, whether husbands who experienced worse physical health were more stressed generally. U.S. researchers, Wright, Hickey, Buckwalter, Hendrix & Kelechi (1999), examined spouse care givers’ experiences who were providing care for persons with Alzheimer’s disease and stroke, especially in relation to their emotional and physical health. The participants represented a convenience sample recruited.
from a university medical centre. Data were collected using Short Zung
Interviewer Assisted Depression Scale, Multilevel Assessment Inventory, Mini
Mental State Examination, and Activities of Daily Living, Instrumental Activities
of Daily Living. There were 42 couples (14 in Alzheimer’s group, 14 in stroke
group, and 14 community controls) in the study. Participants’ ages ranged from
49 to 82 years with a mean age of 67. Findings indicated that AD spouse carers
experienced high levels of depression even in the early phase of the course of the
illness. Significantly, twenty-nine percent of AD spouse carers reported taking
anti-depressant medication at the time of the study. There were no differences
found between male and female carers on measures of depression and physical
health. Moreover, male and female carers’ depression levels and physical health
status did not change over time. However, the sample size was small.

Two of the studies in this category also reported the types of coping strategies
used by carers and the supports available.

Coping Strategies and Supports Available

Researchers Quayhagen & Quayhagen (1988) examined carers’ coping patterns,
management strategies and support factors associated with wellbeing in families
experiencing Alzheimer’s disease. Volunteers were recruited into the study
largely through Alzheimer’s Dementia and Related Disorders support groups.
The sample comprised 17 husbands, 26 wives, and 15 daughters. Measures used
included Life Satisfaction Index, Memory and Behaviour Problems Checklist, Coping Strategies Inventory, Taxonomy of Cognitive Activities, and information was also collected about carers’ perceived physical and emotional health.

Findings indicated that where husbands used physical exercise, for example, taking walks, and cognitively stimulating activities to manage patients, their own wellbeing suffered as wives resisted these attempts. Presumably, although this was not stated, they became discouraged by the lack of success of these efforts. However, respite care was associated with a greater sense of wellbeing for husbands, and husbands were less stressed by frequent dangerous behaviour and embarrassing acts (for example, where wives exposed themselves) compared to female carers. Limitations to generalising study findings included the small sample size and the cross sectional design. It was not evident, therefore, what changes in carers’ experiences occurred over time. Moreover, it was not clear whether all carers were living with the receivers of care. Additionally, 21 care receivers had suffered some head trauma earlier in life. It is somewhat uncertain, therefore, if sufferers’ and carers’ reactions to it were related to Alzheimer’s disease, or the earlier head trauma, or a combination of the two.

Australian researchers, Brown et al. (1995) studied the specific coping strategies carers utilised and were particularly interested in examining any differences in the utilisation of coping strategies between males and females. The study group was formed from volunteers of Alzheimer’s Disease and Related Disorders Society (ADARDS) support groups in six States and Territories of Australia. Eighty-nine
carers agreed to participate and completed self-report questionnaires for analysis by the researchers. Seventy percent of carers were females and the remaining were males. Carers were providing care mostly for wives with Alzheimer’s disease or a related disorder. Findings indicated that men utilised significantly less problem solving coping strategies than female carers. However, the use of such strategies did not always lead to lower burden levels as eventually even these attempts to cope evidently did not change a deteriorating situation. However, the sample members were self-selecting and enlisted from ADARDS support groups, making generalisability of findings somewhat restricted.

In summary, category three studies focussed on carers generally but reported some findings for males. Study findings indicated that males were significantly stressed and readily reacted negatively to care giving events (Anthony-Bergstone et al., 1988). Other studies (for example, Brodaty & Hadzi-Pavlovic, 1990) highlighted that both male and female carers suffered some psychological distress related to feeling isolated and unsupported and where the relationship had deteriorated. Similarly, according to Neundorfer (1991), both male and female carers were stressed, depressed and anxious. High levels of carer depression were also reported by Wright et al. (1999). Elsewhere (Quayhagen & Quayhagen, 1988), husbands’ feelings of wellbeing suffered when wives failed to respond to their attempts to provide physical and intellectual stimulation. Studies of carers’ coping strategies highlighted that older males used less problem-solving coping strategies than female carers (Brown et al., 1995), however, it became clear
eventually that even where these strategies were utilised they were not always successful.

The purpose of the study by Matthews et al. (2004) was to examine the adherence of older male and female carers to recommended preventive health practices. A convenience sample of 319 carer participants 50 and over was recruited from a home health agency in south western Pennsylvania, USA. Information from carers was collected by telephone interview by trained interviewers. Data were also collected about carers’ assistance in relation to care recipients’ activities of daily living needs. Quantitative data were also collected using the Wellness Maintenance and Enhancement Scale of the Health Behavior Markers Scale. Findings of interest to the present study indicated that male carers more frequently received outside help with housekeeping compared to female carers. Moreover, male carers were more likely to rate their health as worse than their age peers. Additionally, males were more likely than female carers to indicate that care giving made them feel useful, appreciated and gave more meaning to their lives. However, care giving was experienced as being more burdensome by male carers.

Elsewhere, Dicker, Chawla & Sudarshan (2006) developed a training package comprising various modules, to assist family carers to manage care recipients’ behavioural and psychological symptoms associated with dementia (BPSD). Carers were both females (n=39) and males (n=11), comprised spouses (n=29),
adult children (n=19) and other (n=2) with a mean age of 63 years. Teaching of carers was carried out on a one to one basis. Research methods employed included a semi-structured interview, 5-item stress/Coping Self-Report Scale, a General Health Questionnaire and a Dysfunctional Rating Scale. Results indicated that carers increased their knowledge of dementia and BPSD, reported being able to manage BPSD better, increased care giving ability and confidence, and experienced less stress. The researchers reported that some carers (often males) were in denial regarding the care recipient’s diminishing abilities and had unrealistic expectations that resulted in increased stress and/or BPSD in the care recipient.

Significantly, gains were still being maintained six months post-training. However, care stress levels had returned to near pre-intervention levels. Positive features of this study included one-to-one instruction at home and the trainer’s ability to explain things. Moreover, all training was undertaken by a single trainer. On the other hand, subject numbers were small and subject recruitment was affected by other studies of carers being conducted at the same time.

Category Four studies were those studies that reported carers’ experiences generally and did not provide any gender specific findings.
3. 8 Category Four Studies

There were twelve Category Four studies. These presented findings related to carers’ experiences but did not identify any results specifically for males or female carers but tended to group results for carers generally. Study findings are reported under the following headings: Impact of care giving on carers, carers’ coping strategies and available supports, care giving activities, and intervention groups for carers.

Impact of Care giving on Carers

Kinney & Stephens (1989) highlighted the role of daily care giving stressors (‘hassles’) and care giving satisfactions (‘uplifts’) on the wellbeing of family carers. The latter had not been studied in any depth by other researchers. The study was a two group design in which family carers’ experiences with a patient group (group one) were compared with those of carers of a non-patient group (group 2). It was not clear, however, how group one was formed. There were 60 carers in group one, of which 81.7% were women. Approximately 50% of carers were spouses. The comparison group (Group Two), comprised men (50.7%) of whom 84.6% were married, and 86.8% were white. Measures used included Caregiving Hassles and Uplifts Scale, and SCL-90-R Scale (a measure of symptomatic psychological stress). Findings indicated that carers experienced high levels of distress and that the degree of their distress was related to care
receivers’ behavioural and cognitive problems, level of ADL assistance received, and the practical/logistical aspects of care giving. Carers, therefore, who cared for more physically limited care recipients reported more hassles with ADL tasks. Where ‘uplifts’ occurred, the researchers suggested that they were associated with greater emotional distress and depression for carers. A possible explanation for this finding is that uplifts are only temporary and the situation in which care is being provided is still inescapable and chronically stressful. It is not clear from the study whether certain things caused hassles or whether those carers who were already distressed found care recipients’ behaviours more irritating. It is also not clear whether certain strategies allowed carers to derive satisfaction from care giving and whether certain strategies provided helpful means of dealing with their negative feelings.

Researchers, Pruchno & Potashnik (1989) examined the impact of caring on the mental and physical health of spouses who were caring for wives or husbands with Alzheimer’s disease or a related disorder. Data were derived from multiple sources and carers were interviewed at three points of time, however, the researchers did not provide any more information about this procedure. The sample was predominantly female (67.7%) and white (86%), had a mean age of 70.1 years (range was 45 to 94) and been providing care for between one month and 20.3 years. The majority of carers were retired. Data were collected using Affect Balance Scale, Hopkins Symptom Checklist, and CES-Depression Index to contrast carers’ levels of depression with others’ experiences from much larger
community databases of non-institutionalised persons aged 20 and over. Results of the study highlighted that care giving spouses were at risk of a host of mental and physical health problems compared to non-institutional people. They were more depressed, expressed higher levels of negative affect, were more likely to use psychotropic drugs and had more symptoms of psychological distress. Generally, carers reported fewer visits to the doctor than did the general population. One possible explanation for this finding is that they were so busy providing care that they couldn’t afford the time to visit their doctor. Another possibility is that there was no one who could take over their role or take them. These explanations would need to be tested in future research. A large proportion of carers (75.8%) rated their own health as the same as or worse that the person for whom they were providing care. All carers were experiencing significant health problems, for example, hypertension, emphysema. A limitation to interpretation of study findings includes that it is unclear how the sample was formed.

Researchers, McGarry & Arthur (2001), examined the experiences of informal carers who were 75 years and over with the aim to identify those ‘at risk’ of physical or psychological breakdown related to the demands of care giving. Potential study participants were identified during one round of annual over-75 year old health assessments carried out in one large general practice. Data were collected through personal interviews and analysed using a thematic approach. Fifty-eight carers were identified and 14 approached to take part in the study. It is
not clear on what basis this selection was made. Of these, 13 were caring for a spouse and one for a sibling. There were 10 female and four male carers in the study (age range 76-92 years). Themes that emerged were: (1 organizational and structure of the caring relationship, (2 informal support networks, (3 formal services, and (4 the constancy of caring and the need for the role of carer to be recognized. Many of the carers in the study were frequently caring under difficult circumstances. However, there was no attempt to measure carers’ level of burden or examine whether they were depressed or not. The writers recommended that where an assessment is routinely carried out at age 75 years of age that this could be invaluable in recognizing older carers who are ‘at risk’. However, in an Australian context a regular assessment of 75 year old adults is not routinely carried out. The researchers proposed that nurses could take a lead role in working with carers by identifying older carers who may be at particular risk, develop strategies to assist older carers in their caring role, and respond to crises where they develop. This recommendation has particular implications for nurses who are working with community elderly clients and those providing care to family members.

The size of the sample restricts the generalisability of findings. In addition, the writers acknowledged that carer-participants did not always understand the purpose of the study. Carers were mostly interviewed alone although this was not always possible and this may have affected what carers shared with interviewers.
Narayan et al., (2001) was also interested in carers’ subjective responses to providing for a spouse with dementia. The sample was recruited from a larger study of family carers of community dwelling individuals with dementia. Data were collected from interviews and completion of the various measures including the Positive Aspects of Caregiving, Caregiving Competence, Relational Deprivation, and Role Captivity Scales. There were 43 carers in the study, being 74% females and 26% males. Ages ranged from 50-88 with a mean of 73. Findings included that carer-participants were experiencing ‘relational deprivation’ and ‘role captivity’. Deprivation referred to loss of intimacy and companionship with their spouse and loss of a social network. Carers who believed good things came from care giving tended to view themselves as self-confident and competent carers. For example, carers used words like “you get closer together” to illustrate this point. Limitations to the generalisability of study findings included the sample size and the need to recruit a more ethnically and socioeconomically diverse sample.

Researchers Shua-haim et al. (2001) in their study, aimed to identify risk factors contributing to the development of depression among carers of Alzheimer’s disease patients. The sample comprised all carers of consecutive Alzheimer’s disease patients of a Memory Disorders Institute. This resulted in 77 pairs of subjects, 30% of whom were male carers. Ages ranged from 55 to 93 (mean 80.4 years). Husbands and wives each formed 49.4% of subjects, daughters, sons, daughter-in-law or son-in-law relationships accounted for 42.9%. Standardised
measures utilised were the Geriatric Depression Scale (GDS), Mini-Mental State Examination, and Katz ADL Scale. The researchers reported that 38% of care givers were depressed. Carers’ depression status was found to be related to the patients’ depression and cognitive status, functional level, and presence of hallucinations. Both age and gender were not found to be risk factors for depression. As the disease progressed first-degree relatives were reported to have a higher rate of depression. An interpretation of this finding might highlight that carers’ depression may have influenced their judgment about whether the patients’ behaviours were bothersome or disruptive.

The study by Helmes, Green, & Almeida (2005) was of interest to this writer as it sought to explore individual differences in carer outcomes according to the personality and behavioural style of the carer as existing models of carer burden had not considered these factors. The design was a cross-sectional, exploratory study which used carer variables of personality traits and mastery and patient variables of cognitive, functional and neurobiological status to predict scores on an established measure of burden (Zarit Burden Scale – Zarit et al., 1986) in a sample of 51 people with dementia and their carers. Measures included the NEO Five Factor Inventory, a cross-cultural instrument representing individual differences in primary personality traits; Pearlin Mastery Scale, a measure of the extent to which the individual believes they can effect positive outcomes; Zarit Burden Scale (Zarit et al., 1986), Katz Index of Activities of Daily Living; and Neuropsychiatric Inventory Carer Distress Scale. Carers were spouses (39.2%),
sons (9.8%), daughters (39.2%), and others (11.8%). Sixty-seven percent of carers lived with the person being cared for. Results indicated that those carers who measured high on the trait neuroticism and who also had a low sense of personal control over significant events in their lives were predisposed to negative affect and low mood. The writers proposed that findings could facilitate identification of those carers who may be ‘at risk’ and enable policy makers to understand that all carers do not have personal resources to cope with their care giving role. The writers also argued that other studies should include personality variables into models that explain dementia carer burden. Study limitations were related to the fact that it involved a convenience sample, the relatively small sample size, and lack of a control group.

There have been few studies of activities that carers engage in while providing care. The following study was a first attempt to provide a description of these.

**Carers’ Coping Strategies and Available Supports**

The aim of Carmack’s study (1997) was to investigate how carers balance engagement in care giving with detachment from care giving to cope with the demands and loses associated with care giving. The research design was qualitative and descriptive and the sample included formal and informal carers in the U.S. The sample size was 14. Data were collected using open-ended interviews and analysed using grounded theory methods. Results indicated that carers who balanced engagement and detachment can affect outcomes although
they may not be able to control them. Through setting and maintaining limitations and boundaries carers were able to monitor the balancing process of providing care and practicing self-care. Although an interesting study, numbers were small and comprised friends and family members providing care (informal carers) and those who were contractually engaged (formal carers). All carers were Caucasian and had a mean age of 48. Informal carers were functioning at a high level and selected into the study where they were identified as effectively balancing engagement with detachment although the grounds on which the selection was made was not clear. It is uncertain whether informal carers were the primary carers. There is no attempt by the author to identify or discuss any weaknesses associated with the study.

A significant finding in Karlin, Bell & Noah’s (2001) study highlighted that carer burden could be reduced where social support was available. The researchers examined the responses of 51 participants to open-ended questions about their experiences as carers of a family member with Alzheimer’s disease. Carers had been providing care for at least eight years and were adult-children (37%), spouses (55%), siblings (4%), grandchild (2%), or distant relative (2%). Results indicated that all carers experienced burden but found some relief when social support, particularly from family members, friends, support groups, was available. However, carers’ feelings of satisfaction about the supports varied and many felt that they did not receive enough emotional support. Interestingly, while most
carers did not report being over burdened, when questioned further they felt that they were suffering from emotional trauma, problems and stress.

By way of criticism of the study, carers were mostly Caucasian (94%). Additionally, it represented a follow-up study from an original quantitative investigation of carers eight years earlier. However, how study participants were selected into the present study was not identified.

**Care giving Activities**

Little has been published in the carer literature that focussed on describing what carers do for those being cared for. Swedish researchers, Jansson, Nordberg & Grafstrom (2001) were interested in this phenomenon. There were eight spouses (6 females and 2 male carers) in their study and data collection included observing carers and those being cared for at home. Grounded theory was used to discover qualities and describe patterns of spousal care giving. Care giving activities included those related to activities of daily living, for example, communication, supervision and physical and mental stimulation. Results indicated that elderly carers were engaged in demanding and time-consuming care and were caring for their partners. Findings certainly assist our understanding of carers’ experiences as there were no other studies that had observed care giving activities in relation to care recipients’ needs. However, the presence of an observer will surely effect those activities. In addition, observation was only undertaken in the daytime and
afternoons. Data about care giving activities also relied on information provided through open-ended interviews. It is uncertain whether observers’ became on occasion participant observers.

Two studies reported on the effectiveness of intervention groups for family carers.

**Interventions Groups for Carers**

Two studies highlighted potentially successful interventions for carers. In one, Ostwald, Hepburn, Caron, Burns & Mantell (1999) described the results of a 3-year randomized trial that tested the effectiveness of an interdisciplinary psychoeducational group intervention in decreasing carers’ perceptions of the frequency and severity of behavioural problems in family members with mild to severe dementia and their psychological reactions to these problems, including burden and depression. The intervention consisted of seven weekly, 2-hour multimedia training sessions. The sessions included education, family support, and skills training. Ninety-four primary carers and their families took part. Carers were recruited from local memory loss clinics and other services, and once they had made contact with the Minnesota Family Workshop they were randomly assigned to a workshop or control group and would take part in a workshop later. The Zarit Burden Scale (Zarit et al., 1986) was used to measure carer burden and the self-report Center for Epidemiological Studies-Depression Scale to measure depression. Frequency of behavioural symptoms and carers’ reactions to them,
were measured using the Revised Memory and Behavior Problem Checklist. Results indicated that carers’ burden levels decreased significantly but this did not occur until several months after the workshop was completed. There was also a trend toward improvement in depressive symptoms. In addition, carers’ negative reactions to care receivers’ disruptive behaviours were reduced but did not significantly reduce the behaviours reported by carers. The delay in carer burden reduction may highlight that stress is mediated by a number of factors only some of which were controlled for by the workshop. However, there was no indication whether carers were also receiving assistance from other services while the workshop was taking place. The workshop utilized a variety of teaching methods, some of which may not have suited the particular learning styles of the carers. It is noteworthy that the workshop offered no continuity or follow-up for carers.

Regarding participants, minority group members were quite low in numbers.

In a second study, Marriott, Donaldson, Tarrier & Burns (2000) evaluated whether family intervention reduced the subjective burden experienced by carers of patients, the majority of whom had Alzheimer’s disease, and produced clinical benefits to the patients. A prospective single-blind randomized controlled trial was employed with three month follow-up in which the experimental group received family intervention and was compared with two control groups. Results indicated that there were significant reductions in distress and depression in the intervention group compared with control groups post-treatment and after 12 months. There were also significant reductions in behavioural disturbance in
carer receivers and an increase in patient activities in the intervention group.

Participants were recruited from hospital-based old age psychiatry services.

However, there was no information provided about how they were identified and included in the study. Carers had to have been living in the community and providing primary care. There were 42 elderly carers included in the study, including spouses (n=10), daughters (n=7) and sons (n=4). An equal number of carers were allocated to three groups: one experimental and two control groups. Neither control group received any specific intervention although both took part in the assessment interviews, with one group receiving an audio-taped semi-structured interview from which the rating of expressed emotion was derived.

Carer assessments included General Health Questionnaire and Beck Depression Inventory (Beck, Ward, Mendelson & Erbaugh, 1961). Patient assessments included the Cornell Scale for Depression and the Clinical Dementia Rating Scale (Berg, 1988). Cognitive-behavioural family intervention comprised carer education, stress management and coping skills training. Study results indicated that family therapy was acceptable to patients and their carers. It was found that the intervention significantly reduced distress and depression and there were no significant differences between the two control groups on these measures. By way of criticism of the study it may be noted that the sample size was relatively small and the intervention lengthy making it difficult to replicate in clinical practice due to resource implications, and the intervention required specialist training. There was no attempt by the writers to compare the care giving experiences of male and female carers.
In summary, category four studies reviewed indicated that carers experienced high levels of distress (Pruchno & Potashnik, 1989; Kinney & Stephens, 1989). Distress was related to care receivers’ behaviour and cognitive problems, level of assistance needed and managing the various components of care giving although it was possible to derive some satisfaction from care giving (Kinney & Stephens, 1989). Karlin et al. (2001) reported that care giving produced a sense of burden and stress. Results from Pruchno & Potashnik’s (1989) study indicated that carers were also depressed and their physical health had deteriorated through care giving. It could be that this was related to the fact that care giving is a time consuming and demanding role as described by Jansson et al. (2001). Shua-haim et al. (2001) found that carers’ depression was related to care receivers’ emotional and cognitive status, and functional level. Elsewhere (Helmes et al. (2005), carers who scored high on trait neuroticism and who felt they lacked a sense of control in the care giving context were found to be depressed.

Being able to remain engaged in meeting care giving demands and at the same time being able to become detached along with practising self-care was more likely to result in more positive outcomes for some carers (Carmack, 1997). However, it was not clear if this approach would continue to be successful as the care receivers’ illness progressed.

McGarry & Arthur’s (2001) study was an important one in that it highlighted for this writer the importance of good nursing assessment of older clients in the
community, especially those carers who may be ‘at risk’ of breaking down into physical and psychological ill health.

Two studies reviewed suggested that a psychosocial group intervention and a family intervention for carers resulted in decreased psychological reactions to care receivers’ problems (Ostwald et al., 1999), and carer distress and depression (Marriott et al., 2000).

3.9 Literature Review Findings in Relation to the Study Topic

Only three of all the studies reviewed in Chapter Three had focused on older husband-carers’ experiences associated with providing care for wives with dementia. These were the studies by Kaye & Applegate, (1990b.) from category one studies, Quayhagen & Quayhagen (1988) and Narayan et al. (2001) from category three. Although the analysis of male carers’ studies fielded some interesting findings, little was discovered about the experiences of older husband-carers providing home-based care for their wives who had dementia and none in an Australian context.

The literature review then highlighted the paucity of studies of the experiences of older males caring at home for their dementia-afflicted wives. Several areas which need to be further examined, and which lend themselves to qualitative investigation are:
1. the distinctiveness or otherwise of the experience of male caregivers;
2. the effects of care giving on husband and the spousal relationship and what these are related to;
3. the needs and problems of male carers, and
4. what supports, if any, are most helpful to male care givers

The purpose of this study is, therefore, to add to the body of knowledge for this specific carer group, and to achieve this outcome in two stages: the first using open-ended and unstructured interviews with older husband-carer participants and the second using a comprehensive questionnaire supported by standardised measures which allowed an examination of relationship between the variables of interest. But, how is the concept of carer conceptualised in the literature and in particular how is it conceptualised in this study.

3. 10 Carers

An examination of the literature since 1976 revealed a variety of ways in which carers have been conceptualised by writers and researchers. In some studies, a definition of carer was restricted only to those who are the primary carers or to those who are seen as providing most of the care (for example, Brown et al., 1995). George & Gwyther (1986) have identified as carers those who provided assistance and included friends and neighbours, to the live-in carer but these might more appropriately be termed back-up or secondary carers.
Elsewhere, Brown et al. (1995) have described a carer as a person who lives with the care receiver. According to this definition, the person provides care whilst living in the community rather than within an institutional setting. Elsewhere (for example, Pratt, Schmall & Wright, 1987), carers were described as those spouses and other relatives who were providing care to family members both at home and for those who had been institutionalised, for example, in a nursing home, or were living elsewhere, for example, in a retirement village). In other studies, the relationship between the caregiver and the person receiving care has defined the care giver, that is, the carer is usually a family member, often a daughter or wife (Mittelman, 2003) a spouse (Brown et al., 1995), or other relative (for example, brother or sister, nephew or niece, son-in-law or daughter-in-law) in Brown, Holmes & Mitchell (1991). For other researchers, carers are those family members who attend support groups (Robinson et al., 2001) since such support groups have been a valuable source of subjects for research purposes. Such an approach raises issues about the representativeness of the samples and therefore of the results.

What is clear from the above review is the inconsistent manner in which carers of those who are dependent in some way have been defined. However, just as care giving is a very individual experience, carers’ characteristics also vary between individuals. Similarly, the ways in which individual carers react to their care giving situation will be unique although there may be some common experiences too. None of these concepts are particularly clear or helpful in the search for a
definition of ‘carer’.

Although it may be desirable to provide a prescriptive definition of carers to introduce comparative controls in statistics-based research studies, doing so will reduce the richness of the phenomenological data that could be derived by accessing the experiences of those persons who identify themselves, or are identified by others, as carers. Perhaps the most useful definition of carer, then, is the one that restricts the term primary carer to those having primary responsibility for the provision of informal, home-based care.

In the present study, carers were defined as older husbands (usually over 65 years of age) who were the primary carers of wives with dementia at home. Some were attending support groups and others were not.

The literature review highlighted that many carers experienced emotional and other consequences associated with care giving although this was not always the case. In the next section, the negative consequences are examined.

3. 10. 1 Carers and Burden

It is evident from the literature review that various studies have reported that carers of family members with dementia commonly experience negative emotional consequences associated with care giving. Studies describe this
phenomenon using different terms, for example, burden (Neufeld & Harrison, 1998), stress (Patterson, Semple, Shaw, Yu, He, Zhang, Wu & Grant, 1998), psychological distress (Patterson et al., 1998), psychological response to the stress of caregiving (for example, Patterson et al., 1998), and strain (for example, Kramer, 1997; Almberg et al., 1998).

Kramer (1997), states that the “more negative appraisal of strain” is referred to as burden. Early researchers, Poulshock & Deimling (1984), defined burden as the caregiver’s appraisal of distress that results from the care receiver’s physical dependence and cognitive decline. Elsewhere, Schulz et al. (1990) suggested that burden is related to the physical demands associated with loss of sleep, carers’ declining health and breakdown in relationships. It is also clear from the literature that caregivers have been largely unsupported thus adding to their sense of burden. As reported by the ABS (2002), over half of all principal care givers did not receive any support or help with caring from family, friends, or formal services.

Concepts of Subjective and Objective Burden

According to Pearsall (2001) burden is “a load, typically a heavy one” (p.243). While this aptly describes the experience of some it is not necessarily so for all care givers since what is perceived as ‘burden’ by one person may not necessarily be perceived in this way by another. For example, in the context of the present
study, one male may not have found it difficult to take over his wife’s role within the home or carry out personal care activities, whereas another might have found it quite difficult. This view of burden stresses that the experience of burden is related to people’s feelings about, evaluations of, or reactions to, in the above example, changing roles. This has been described in the literature as ‘subjective’ burden (Butcher et al., 2001).

The second view of burden is that it is associated with and arises from particular events and activities. In the case of family care giving, this could be disruption to family life associated with time and effort involved in providing care. Inherent in this approach to burden is the thought that the person receiving the care is the source of burden as the problems experienced by the carer are related to the family member’s illness-related behaviour. This concept of burden has been described as ‘objective’ burden and equates to aspects of the care giving situation (DiBartolo, 2000; Ohaeri, 2003). However, one could argue that viewing burden in this way makes it difficult to differentiate between care givers’ role conflict and the distress associated with role conflict. Moreover, the present writer would argue that both subjective and objective ‘burden’ will be experienced by most caregivers at some point.

Burden as Threat to Carers’ Basic Needs

According to Braithwaite (1990), threats to carers’ basic needs are central to the
notion of burden and may cause carer distress. She argues that this conceptualisation of burden recognises the place of subjective evaluation and carers’ assessment of the threats in their situation, and at the same time acknowledges their objective evaluation of the situation. However, Braithwaite’s model of care giving encompasses the experiences of care givers generally. It is not known, therefore whether males’ experiences associated with providing care for wives with dementia differ in any ways to wife-carers’ experiences or whether all care givers’ experiences of burden as described are explained by this explanation. As well as feeling a sense of burden, some studies suggested that some carers were also depressed.

3. 10. 2 Carers and Depression

Levels or degrees of depression have been identified through the use of various standardised measures, including the Beck Depression Inventory (Beck et al., 1961), the Hamilton Rating Scale, the Centre for Epidemiological Studies Depression Scale and the Geriatric Depression Scale. It is clear from a review of the literature that in several studies (for example, Parsons, 1997; Neufeld & Harrison, 1998) that carers of family members with dementia experience greater depression than carers of family members with other conditions, for example, medical disorders, and that generally, female carers experience more depression than male carers. It should be pointed out that carers’ burden and depression are not separate experiences as feeling burdened may result in feelings of depression.
and being depressed will increase a sense of burden.

In the present study husbands’ level of depression is examined more formally in Stage Two using the Beck Depression Inventory (Beck et al., 1961) as (1) there were indications from Stage One interviews that husbands were experiencing at least some depressive symptoms, and (2) little was known about the phenomenon of depression in husband-carers and what experiences or factors this might be related to.

3.11 Conclusion

A review of the carers’ literature revealed that there were thirty-seven studies that had been carried out since 1983. Of these, only eleven had as their focus male care givers although an additional sixteen studies had focussed on comparing the differences between male and female care givers’ experiences or examined carers’ experiences generally and reported some findings for males. Of the studies reviewed only three had explored the care giving experiences of older husbands who were providing care in their homes for wives with dementia. There were no studies carried out in an Australian context reported in the scholarly literature.

Researchers’ recommendations for further research in relation to male carers were
incorporated into either stage one or stage two of this study as the basis of research interview questions or as questionnaire items. The next chapter describes the methodology used in the study.
CHAPTER FOUR

THEORY AND METHOD

This chapter describes the development of the methodology that was utilised in a two stage study. A qualitative approach paradigm was employed in Stage One to study older husbands’ experiences of care giving. Findings assisted in the development of Stage Two in which the relationship between variables of interest and measures of burden and depression were examined quantitatively.

Introduction

In the previous chapter the literature regarding family carers’ experiences was reviewed. This review uncovered only a few overseas studies of husbands’ experiences and none within an Australian context. To increase our understanding of this phenomenon in an Australian context, the researcher developed a study in two stages. In stage one, reported fully in the following chapter, the researcher interviewed seventeen older men who were providing care for wives who had been diagnosed with dementia. These interviews conducted in the men’s homes, used open-ended interview questions to elicit their experiences. Stage one utilised grounded theory methodology, informed by a Symbolic Interactionist perspective, and content analysis to identify themes and patterns.
from the data. From the data, three models of husbands’ care giving related to the Past, Present and Future and an overall model of care giving over time, were identified and will be described in Chapter Five.

Findings from Stage One, along with a further review of the literature and discussion with informed professionals, family carers and the researcher’s supervisor, guided the development of a comprehensive questionnaire, containing the independent variables of interest. In addition, several standardised measures (the dependent variables) were identified to examine the combined and separate contributions of eight “cluster” variables (independent variables from questionnaire organised into recognisable clusters), to the variation of each of the dependent variables (for each of which a single group score was statistically derived) using multiple regression analysis. Findings are discussed in Chapters Seven. In addition, descriptive analysis of the variables of interest to the researcher is presented in Chapter Six.

In overview, this chapter introduces the philosophy of disciplined research, broad research paradigms (naturalistic and positivist) as well as the particular qualitative and quantitative research methods used in this study, including analytical approaches. More specifically, the use of content analysis and grounded theory to analyse interview data (stage one), and the analytic tools used in interpreting questionnaire data (stage two), will be described.
4.1 Research Paradigms: An Overview

Research is an important way of finding new knowledge and restructuring existing knowledge (Burns & Grove, 2005) and this is achieved through the use of research paradigms to study the phenomena of interest. Until recently, research paradigms have comprised a set of basic beliefs about the nature of phenomena which could be investigated (Monti & Tingen, 1999) and the choice of appropriate methods for scientific inquiry rested mainly with a quantitative paradigm (Crookes & Davies, 1998). It is now widely acknowledged that scientific inquiry is less a matter of preferred paradigm and more a matter of selecting the most appropriate research paradigm for the phenomenon to be investigated. Additionally, viewing a paradigm as a “…general scientific perspective or tradition” infers that researchers apply paradigms to solve problems regardless of their philosophy and perspective through which phenomena can be viewed (Monti & Tingen, 1999, p.65).

According to Polifroni & Welch (1999, p.22) a paradigm reflects a perspective from which a field of study can be conceptualised to capture “the assumptions that are inherent in that view, and the basis on which knowledge claims are accepted”. For Bailey (1997), paradigms are often based on approaches formed in answer to a set of complex questions including:

- The nature of reality? (Ontologic paradigm);
• The relationship between the inquirer and that which is being studied? (Epistemological paradigm);

• The role of values, ethics, aesthetics in inquiry? (Axiologic paradigm);

• Ways in which the inquirer obtains knowledge? (Methodologic paradigm)

Broadly speaking, disciplined inquiry is conducted mainly within two research paradigms. The one with the longest established tradition is the Positivist paradigm, also referred to as quantitative, scientific, or empiricist. In such studies, data are captured and interpreted numerically (Polit & Beck, 2004). The second paradigm, Qualitative-interpretive (also known as naturalistic), lends itself to rigorous investigation of subjective phenomena generally not accessible by quantitative research. It can be further divided into two sub-types: 1) Qualitative interpretive research, and 2) Qualitative critical research. Qualitative interpretive research attempts to make sense or interpretations of phenomena as they occur in naturalistic settings and the meanings people bring to them (Gittins, 2002; Roberts & Taylor, 2002). Qualitative research has methodological and philosophical subdivisions stemming from distinctive philosophical viewpoints. Early major divisions within the interpretative tradition were phenomenology, ethnography, and grounded theory (Lowenberg, 1993). Such a division, however, is somewhat simplistic and omits other important components. Alternate and more complex classifications, therefore, have been proposed by Polit & Beck (2004). Qualitative critical research includes action research, feminist research, interpretative interactionism, discourse analysis and critical ethnography (Schwandt, 2000).
From the writer’s understanding, and in addition to these philosophical issues, what distinguishes the conduct of quantitative and qualitative research is methodology or the differences in approach to sampling, data analysis and interpretation, and in the definition of ‘rigour’ (see point 8, Section 4.1.1).

When research is being planned, one fundamental issue to consider is the nature of the research question (or questions) to be investigated. If the questions involve How much? How many? How often?, the researcher will generate numerical data and require a sample of sufficient size for statistical processing. If the questions focus on subjective issues of feelings about, interpretations of, and responses to, particular experiences, decisions about sampling will focus on who has had the experience and sample size may not be such a crucial issue and lend themselves to the use of qualitative research methodologies and methods. The term qualitative research is used then to describe both a paradigmatic perspective and a particular type of data collection. The former is a “methodology” and the latter a “method” (Crotty, 1998, p. 5).

Both paradigms have much to offer the researcher. As noted above, quantitative research is closely allied with the positivist tradition and qualitative research with naturalistic inquiry. However, quantitative researchers sometimes engage in qualitative research and qualitative researchers sometimes engage in quantitative research (Tashakkor & Teddlie, 2003). Moreover, Roberts and Taylor (2002) and Ezzy (2002) have identified that there are some similarities between the two
paradigms since both can employ deductive and inductive thinking, require ‘scientific’ designs, and show themselves to be rigorous. Whilst some researchers, for example, Crookes & Davies (1998), argue on philosophical grounds that one type of research precludes the other, others, such as Roberts & Taylor (2002), assert that it is possible to use both paradigms in a given study, gathering data reflecting distinctive aspects of a research question thus achieving richer data and broader interpretations (Tashakkori & Teddlie, 2003).

Some studies naturally lend themselves more to qualitative types of research, for example, attempts to understand a person's experiences with addiction or recovery from a stroke, and can be used to uncover and understand what lies behind human phenomena such as those about which little may be known (Patton, 2002), for example, husbands’ care giving experiences. A relatively small sample of husbands in stage one was interviewed using broad questions with follow-up probe questions for eliciting and clarifying their experience. Quantitative research was utilised in stage two of the present study in the form of a survey-questionnaire, with accompanying standardised measures and using a larger sample to further investigate the phenomenon of interest, since the researcher believed that using more than one paradigm would provide different and more comprehensive views from which to examine the phenomenon of interest.
Each research paradigm will be examined in more detail, beginning with the stage one study. Following a general overview of qualitative research, particular aspects of the stage one study will be discussed. Stage two of the study will be explained further in this chapter.

4.1.1 Qualitative Research Methodologies

Qualitative research is often carried out in the social, educational and behavioural sciences and can be used to study organisations, groups and individuals (Strauss & Corbin, 1990). Qualitative research is characterized by the following:

1. Initial literature reviews may or may not be undertaken at the proposal writing stage, depending on the study methodology. A return to the literature at various points throughout the study is common (Schneider, Elliott, LoBiondo-Wood & Haber, 2004).

2. Sampling is purposive, that is, there is deliberate recruitment into a study of those who have had broadly similar experiences, and who meet justifiable inclusion criteria. Samples are generally smaller than required for statistical analysis (Polit, Beck & Hungler, 2001).

3. Sampling of individuals or small groups may be sequential, that is, not before some preliminary data analysis from earlier interviews has been done (Cutcliffe & McKenna, 1999).
4. People recruited into qualitative/interpretive studies are referred to as ‘participants’ or as ‘informants’ (as distinct from ‘subjects’), which provides a focus for individualization and personalization of research interviews, but without compromising the neutral stance of the researcher (Brockopp & Hastings-Tolsma, 2003).

5. Data are able to be collected in several ways including by observation; participant observation; interview; and/or recourse to relevant documentation (Denzin & Lincoln, 2000).

6. In some qualitative research methodologies, for example, grounded theory, early data analysis may begin at the time of data collection, and may even become a crucial factor regarding what further data are collected during and subsequent to any given interview (Minichiello, Sullivan, Greenwood & Axford, 2004).

7. Data analysis is continuous until convincing clarity of findings emerge, and in many instances, is validated by as many informants as can be contacted. Memos are written and reflected on during the course of the study by the researcher (Berg, 2004).

8. Standards of rigour in qualitative research effectively mean that every aspect of the project from ethical issues to write-up reflects a high level of competence, thorough knowledge of the selected methodology, consistent integrity of the researcher, and
adherence to standards of rigour in qualitative research which have been developed, (see Ezzy, 2002; Chiovitti, 2003; Seale, Gobo, Gubrium & Silverman, 2004; Liamputtong & Ezzy, 2005).

Development of the naturalistic or interpretive paradigms over several recent decades represent a reaction to or shift away from positivism in some disciplines and challenges the limitations and problems of quantitative methodology in studying subjective experience (Sheldon, 1998). Most recently, the Cochrane Collaboration has conducted rigorous systematic reviews of interpretive research but others, for example, Evans (2003) have highlighted that the best approach for the “synthesis of interpretative data is not clear and existing reviews have used a range of different methods” (p.23).

4.2 Stage One Study: Research Design

In stage one, grounded theory from a Symbolic Interactionist approach was used to study the care giving experiences of seventeen husbands who were interviewed at home. One withdrew from the study before the data were analysed, leaving an effective data base of sixteen informants for analysis. In stage two, quantitative research methods were utilised to examine through a self-report questionnaire and standardised measures, the experiences of a larger sample of husbands. The researcher believed that using both qualitative and quantitative methodologies
would provide a more complete and accurate picture of the population of interest (husband-carers), and increase the breadth and depth of information about this group, thus providing a more holistic view of their world. This approach is referred to in the literature as triangulation.

4.2.1 Triangulation

Triangulation is used to examine complex social issues, and provide a rich explanation of the phenomenon being studied (Cutcliffe, 2000; Brockopp & Hastings-Tolsma, 2003; Minichiello et al., 2004). Cutcliffe describes four types of triangulation: data, investigator, theoretical and methodological. Data triangulation describes the use of multiple data sources having a similar focus to obtain divergent views about a particular phenomenon. Investigator triangulation occurs when two or more skilled researchers examine the data. Theoretical triangulation relates to the use of all possible theoretical interpretations as the framework for a study enabling hypotheses to be developed from different theoretical backgrounds, to be tested against one another (Minichiello et al., 2004).

Methodological triangulation involves the use of two or more research methods in one study to inform design or data collection (Sarantokos, 2005). There are two types of methodological triangulation: within-method and across-method. In the former, strategies are combined from two or more research traditions, for
example, quantitative and qualitative. Across-method triangulation involves combining two or more similar data collection approaches in the same study to measure the variable of interest. In methodological triangulation the results of one method are necessary for the planning and implementation of another (Denzin & Lincoln, 2000).

Gittins (2002) argues that triangulation does not guarantee internal and external validity and may in fact compound sources of error. Moreover, the particular methods selected may be unsuitable and others more appropriate. Sarantakos (2005) highlights that researcher bias might still be a problem in triangulation and replication difficult, and using two research paradigms is likely to make the study expensive and time consuming.

Stage two of the present study is an example of within-method, sequential, methodological triangulation since two different research methods, grounded theory and descriptive correlational research, were used at the level of design, data collection, and analysis. Specifically, the results of Stage One were utilised to plan and implement Stage Two of the study, supported by further reviews of the research literature, discussions with family carers, aged care services staff, and the researcher’s supervisor. In stage two, a questionnaire was developed, standardised measures were identified and selected to investigate male carers’ experiences further.
4. 2. 2 Relevance of Qualitative Approach for Stage One of the Study

As stated earlier, in stage one of the study a qualitative research methodology was utilised to examine husbands’ care giving experiences. As described in section 4.1, qualitative methods are appropriate for those questions which primarily require inductive analysis through description and interpretation of human experiences, in this case, husbands’ care giving. Specifically, the central research focus of stage one was to describe their experiences while providing care for wives at home who had been diagnosed as having dementia so as to better understand the meaning of their experiences and perceptions of their role. In stage one, grounded theory from a Symbolic Interactionist perspective was used to study husbands’ home-based care giving experiences of caring for wives with dementia in order to develop a substantive theory of their care giving.

4. 2. 3 Stage One Research Epistemology: Symbolic Interactionism

Symbolic Interactionism is a social-psychological theory of social action (Gittins, 2002) which allows the researcher to explore the way people define their contextual or symbolic realities and how beliefs are related to their actions (Glaser, 1994; Ross, 2002). Moreover, the Symbolic Interactionist is interested in identifying common sets of symbols and understandings that give meaning to people’s interactions (Patton, 2002). Symbols include words, behaviours, roles, objects, which are interpreted and become the basis for expectations, actions,
interactions and reactions (Denzin & Lincoln, 2000; Polit et al., 2001; Sarantakos, 2005). While many symbols have common meanings they can be unique for each individual, for example, in the present context, for each caregiver. However, broad meanings (that is, concept of carer) may be shared by family carers who attend support groups. Shared meanings are taken up by new members (new family carers), through socialization processes (as they attend a carers’ support group and listen to other carers speaking about their own experiences). The present writer believes that meanings are not completely transferable among male carers in similar situations but arguably they might guide general modes of response towards problem behaviours of their wives who have dementia.

From the Symbolic Interactionist perspective, the purpose of the present study was to understand what husbands and others (such as other family members), know about their world and what they believed was important. As we have seen already, symbols are unique to each individual and commonly care givers communicate experiences through symbols (Denzin & Lincoln, 2000). When a symbol is shared by others around the carer, such as other carers, it may allow them to interact in a more predictable way. For example, we might find that family carers use a particular language or terminology to communicate their experiences to each other. If non-caregivers were to listen to these descriptions it may take them a while to ‘tune in’ to their meanings whereas carers may quite readily understand what other carers are describing. Interpreting symbols from others then, or taking in messages about how to act, enables carers to adjust their
own actions accordingly. According to the Symbolic Interactionism perspective, the husband who is trying to interpret the world of carers may be influenced by others (for example, carers, aged care team members) as he attempts to understand what others would do in a similar situation. There could be a common set of symbols to be relied upon, as many older people would have had various care giving responsibilities throughout their lives. But, in a very real sense the object (care giving for a family member with dementia), has limited meaning as the individual has not experienced care giving in this particular way before.

Blumer (1980) describes that within Symbolic Interactionism, objects are anything that can be reflected on and have no inherent meaning in and of themselves but are defined by the meaning they have for the individual who acts upon them (see also Simmons, 1995; Denzin & Lincoln, 2000). Meanings (or ‘realities’) therefore, will vary from one individual to another and one context to another. Within this theory, roles (such as carer), result from a dynamic, interactive process between the self and the social context (Cutcliffe, 2000; Denzin & Lincoln, 2000). Accordingly, husband carers can be expected to act differently to their situation according to their history of social experiences, some having had previous experiences with care giving (looking after older parents or their own children) whilst others will have little or no experience.

According to Symbolic Interactionism, it is through social interaction that the individual achieves a sense of self (Sheldon, 1998). This process begins at birth
and continues through ongoing social interaction throughout one’s life. The *self* is composed of the *I* and the *Me*. The *I* interprets, considers information, evaluates, and relates it to the *Me* (Bowers, 1988). Moreover, each individual is comprised of multiple selves or *multiple Me’s*, for example, husbands in the present study were carers, but also husbands and fathers, and some were still sons. Multiple selves, therefore, may exist simultaneously but they may also change over time, for example, husband-carers may have been husbands and workers for many years but now find themselves retired and providing full time care. *Multiple Me’s* may make care giving difficult and may place some carers at risk of physical and psychological breakdown. For example, a husband who is providing care for a wife with dementia and continues at the same time to support a frail parent, may sooner or later find this situation intolerable and be tempted to place his wife in a nursing home earlier than expected. With respect to the present study, the *Me* who plays the role of ‘husband’ may have to change to incorporate the *Me* of carer, particularly when his wife’s illness-related problem behaviours become more severe requiring constant care and attention. Sometimes, conflicting *Me’s* emerge, for example, husbands may experience difficulties carrying out personal care activities, for example, toileting their wives, and may result in them questioning who they are (carer, husband or parent).

According to Denzin & Lincoln (2000), the way objects or roles are perceived also evolves over time. For example, initially, in the care giving role, a husband could feel quite overwhelmed, but as time goes by he may become more at ease
and accepting of the situation he finds himself in. Individuals also learn the meanings of objects or behaviours by observing and interpreting the way others act. For example, for a husband-carer who listens to others’ experiences of care giving at support groups, the object ‘carer’ becomes defined for them. In terms of the present study, some husband-carers, may have similar meaning systems to other family carers, both male and female, generally as a result of support group attendance. Male carers, however, may develop meaning systems that are at odds to those of female carers, for example, husbands’ model of care giving may be based back in the workplace, whereas, females’ model may be based in the mother-child relationship.

According to Symbolic Interactionism, things are real in their consequences, for example, if health professionals act toward husband-carers as if they are ‘doing a bad job’ they may in turn experience the role negatively. The end result may be that husbands place their wives in long-term care prematurely. Realities may also become objectified and internalised by individuals and others (Denzin & Lincoln, 2000). For example, the socially constructed "reality" of husband-carers may become an institutionalised model, with Aged Care Assessment Team members viewing husbands as experiencing more difficulties with care giving compared with female carers, and this may determine what services they receive, for example, they may provide husband carers with more support and female carers with less.
In stage one of the study, grounded theory from a Symbolic Interactionism perspective was used to study husbands’ care giving experiences. It is described in the following pages.

4.2.4 Stage One Methodology: Grounded Theory

Unlike other epistemologies, such as ethnography and phenomenology, grounded theory is primarily a methodological strategy (Kushner & Morrow, 2003) that allows the researcher to generate a substantive theory through the development of working hypotheses (Ross, 2002). According to Ezzy (2002, p.7) it “rejects the ‘logico-deductive’ method of theory building and verification which begins with an abstract theory, deduces some implications, formulates hypotheses, and then develops experiments to verify or otherwise the hypotheses”. Sheldon (1998) argues that if hypotheses are constantly being fine-tuned, the developed theory will reflect participants’ realities and a deeper understanding of the phenomenon under investigation rigorously which is grounded in the data.

Grounded theory was developed in the 1960’s by Glaser and Strauss (Gittins, 2002) and had as its purpose the study of social phenomena, for example, human interaction, from the perspective of Symbolic Interactionism (Roberts & Taylor, 2002; Kushner & Morrow, 2003). Burns & Grove (2005) inform us that it is a useful research approach when little is known about particular aspects of the problem under investigation, for example, husbands’ care giving experiences, or
when much about the problem has been assumed by others, for example, clinicians and even researchers. Grounded theory examines the effects of social behaviour, as noted above, differentiating it from ethnography which focuses on the culture of a group of people so as to determine how people in that culture view the world (Polit et al., 2001), although the two perspectives share several data collection methods. It differs from phenomenology which attempts to explore the lived experience of a person or persons (Roberts & Taylor, 2002).

According to Ross (2002), grounded theory uses a systematic set of procedures to develop an inductively derived theory so as to capture the complexity of an individual’s or group’s reality and allows the researcher to make sense of it. Bailey (1997) argues that the collected data should be comprehensive and the derived conceptual interpretations broad. Moreover, he proposes that where concepts are systematically developed from the data, then a grounded theory should be applicable (as distinct from generalisable) to a variety of contexts. But, what is the role of researcher in grounded theory?

4.2.5 Role of the Researcher in Grounded Theory Research

In order to discover what the world of informants is like and how it is constructed and experienced, the researcher attempts to balance two investigative modes. The first involves establishing relationships with people, places, and performances (Ezzy, 2002). This is achieved through *immersing* oneself in the world as seen
through the eyes of informants. To achieve this data are collected primarily
through focused, semi-structured interview and document review and participant
observation (Sarantakos, 2005). Secondly, through *distancing* the researcher
stands back from the data, to ask questions of it, compare the accounts of
individual informants with each other, and reflect on his or her own understanding
of the data, a process known as the 'constant comparative method' (Schneider et
al., 2004). Relevant literature may be consulted as analysis proceeds and is
consulted from time to time during the research. The present study provides an
example of these processes. In examining the interview data the researcher may
find that the carers and/or their families have a different definition of care giving
from those found in the literature. For example, the researcher might find that
informants’ perceptions of care giving are more akin to "psychosocial care" than
those, described in the literature, that are based more on instrumental tasks, for
example, bathing, lifting, feeding. Such a markedly different finding would
compel the researcher to re-examine the data to confirm (or disconfirm) some of
their own findings, as well as to examine the basis on which different conclusions
have been drawn in the literature. Whilst offering much to the qualitative
researcher, grounded theory has been criticised by some. These are described
next.

4. 2. 6 Criticisms and Difficulties of Grounded Theory and Symbolic
Interactionism

Kushner & Morrow (2003) propose that grounded theory attempts to ground itself
in the positivist perspective so as to be more accepted by positivist researchers. Moreover, it may be noted that grounded theorists employ terms such as variables, hypotheses, theoretical sampling to supposedly improve its acceptability. Keddy, Sims & Stern (1996) argue that using terms such as these may cause frustration and problems for many qualitative researchers. Keddy et al. (1996) propose that grounded theory’s reliance on Symbolic Interactionism can be a strength and weakness. It is a weakness in that the latter denies that it is aligned to any specific theoretical perspective. Moreover, according to Kusner & Morrow (2003), Symbolic Interactionism fails to reconnect face-to-face accounts with structural contexts, and can obscure the relations of power that inhibit marginal groups to voice their experiences. Elsewhere, Johnson, Long & White (2001), have argued that grounded theory lacks rigour as there is not always clarity about the methods used. Clearly, personal involvement of the researcher always raises issues of subjectivity and possible bias in relation to data collection processes and analysis of the data (Sarantakos, 2005). Significantly, Seale et al. (2004, p.80) argues that there is no such thing as ‘grounded theory’, that is, a single, unified methodology, tightly defined and clearly specified but different interpretations of what grounded theory involves.

According to the literature, grounded theory includes a process. A commonly used process employed by many grounded researchers is described next. If we accept Seale et al’s (2004) argument above, then we might find that researchers using grounded theory might also vary in relation to the steps employed and even
the order in which they are operationalised.

4. 2. 7 Research Process in Grounded Theory

Grounded theory differs from most other research methods in relation to the steps in the research process in the following ways: (1) the literature review, questions/hypothesis generation, data collection, and analysis occur simultaneously (Ross, 2002); (2) ongoing data analysis guides the development of interview questions and informant selection; and (3) the interview questions, research questions, and hypotheses become modified as the process proceeds (Ezzy, 2002). Theory development allows more focussed questions to be put to informants, a process known as theoretical sampling (Schneider et al., 2004). Glaser (1992) however, argues that theoretical sampling begins with initial data collection. The theory that develops is comprised of themes, codes or categories and they provide the means of classifying data (Sheldon, 1998). This process is continued until saturation of themes or categories is achieved, that is, until new data, for example, information derived from additional interviews do not show any new theoretical elements (Liamputtong & Ezzy, 2005).

One common approach to data collection used by grounded theory researchers is the interview of informants selected on the basis of their experience of the phenomenon being studied.
4. 2. 8 Data Collection Approaches in Grounded Theory

Interviews usually begin with a fairly general research question, for example, "What has it been like to care for a family member with dementia?" This provides an invitation to explain or describe their experience (family care giving) in the way they perceive it, the interviewee being acknowledged as the expert in describing their care giving (Tashakkori & Teddlie, 2003).

According to Patton (2002) data may also be collected from various sources including documents, media items, informal conversations and participant observation. Whilst participant observation enables the researcher to observe, participate in and ask questions about those observations, this approach is not always possible. For example, in stage one the researcher aimed to conduct interviews with husband-carers in their homes and to observe their care giving behaviour, activities and interactions. After several interviews, at which wives were present, it became evident that this approach was not going to be satisfactory because of the negative effects that the researcher's presence had on wives, specifically they became agitated, suspicious about why the researcher was present and verbally aggressive towards the researcher and their own husbands. Sometimes then, the researcher's access to the subjects will have to rely on other methods for data collection and in stage one the primary data source was the interview.
In the present study, indepth interviews were employed as they allowed the researcher to explore husbands’ thoughts and feelings about care giving. An interview describes how two people, often relative strangers, sit down and talk about a specific issue or topic. Indepth describes “a style of interview that encourages interviewees to produce ‘thick descriptions’…, elaborated and detailed answers” (Seale et al., 2004, p.15). Interviews enabled husbands to describe their own unique experiences and perceptions of care giving, and allowed the context in which care giving was provided to be described and examined. Typically interviews are recorded and transcribed which in themselves raise various issues.

4.2.9 Transcribing Interviews

Although Strauss & Corbin (1990) have stated that researchers should transcribe only as much of the interviews or field notes as is needed, clearly, exactly how much is needed will not be an easy decision to make. The authors, therefore, suggest that if this is the researcher's first study or the study is small scale with relatively few interviews or field notes, then it is wiser to transcribe all of the materials and that the very first interviews or field notes should be entirely transcribed and analysed before going on to the next interviews or field observations. Field notes are notes recorded before, during and/or after an interview (Seale et al., 2004) and document information about the setting, participants, and salient aspects of the interviewer’s responses. This early coding provides guidance to the next field observations and/or interviews. Later, as the
theory develops, the researcher may wish to examine the transcripts and transcribe only those data that relate to the evolving theory. In the present study all data were transcribed verbatim and analysed by the researcher. Early manuscripts and interpretations were discussed with the researcher’s supervisor. Field notes were entered into an exercise book to provide broader description about the care giving context. At this point, coding, which involves sorting, labelling, and categorising data, was engaged in.

4. 2. 10 Coding

Codes may be simple, topical categories or more abstract conceptual categories in an emerging theory. Codes may be derived from many sources (Denzin & Lincoln, 2000; Patton, 2002). In the present study codes were developed from interview data and field notes. According to Burns (2003) codes are identified by closely examining participants' statements for patterns, inconsistencies or contradictions. The researcher then defines how participants act upon their assumptions, for example, how care givers’ behaviour is based on what they have heard other carers describing as their experiences of care giving (Roberts & Taylor, 2002).

Coding comprises a searching phase and a later phase of focused coding. It enables the researcher to develop and manipulate ideas, focus on the context, for example, in which care giving occurs, the participants, their roles, how they
structure events and the relative emphasis they place on various issues described by them. Coding assists the researcher to look for connections between situations, problems and interpretations of participants’ experiences (Denzin & Lincoln, 2000; Liamputtong & Ezzy, 2005). The researcher codes about what participants stress as well as what they don’t. The data can also be scrutinised for ‘in vivo’ or verbatim codes, for example, a husband who described his reaction to care giving in the following way, “Thank God its not cancer”. As relationships among the categories are discovered, tentative hypotheses are developed by the researcher (Miles & Huberman, 1994). In focused coding the researcher takes the codes that were developed in the initial searching phase and applies them to large amounts of data (Miles & Huberman, 1994). It can also be used to develop subcategories (Liamputtong & Ezzy, 2005). Knowledge of the literature may also be used to expand and clarify the codes and to guide the exploration of the emerging analysis (Denzin & Lincoln, 2000). The developed categories serve as a framework and help provide the groundwork for developing explanations and predictions.

The grounded theorist is also interested in the strategies used by participants by which "reality" is constructed or maintained by the participants involved. First, the researcher defines the core category and related categories. Next the researcher identifies the strategies used by participants to carry out the phenomenon being studied (Patton, 2002). The ‘actors’ (for example, family members, aged care nurses, support group members) may have very different perceptions about the phenomenon (family care giving) and will act towards care
givers in particular ways (for example, they may offer more support, or may feel that the carer is making too many decisions on behalf of the patient, thus taking away their independence).

Identifying the conditions under which a particular phenomenon occurs is also a central task of the grounded theory researcher, for example, it might be found that caregivers experience increased burden as their wives’ cognitive functioning deteriorates. What might also be found is that under these conditions, male carers may not acknowledge their burden to outsiders. These hypotheses could then be tested by further data collection and analysis.

4.2.11 Memoing or Field Notes

Memoing is an important process for the grounded theory researcher and provides an ongoing account of the researcher’s thoughts and decisions in relation to theory development. It also provides a record of decisions made about sampling (selective and theoretical), changes in the focus of interview questions and the development of tentative hypotheses. Memoing assists the researcher to keep track of his or her responses to data collection and analysis, including the possible meanings of the data (Polit & Beck, 2004). Memos may be used to record ideas that were not pursued for various reasons as well as methodological decisions or problems (Schneider et al., 2004).
In the present study, an A4 exercise book was used to record a description of the physical context in which care giving was occurring, impressions arising out of the interviews and concepts from the literature analysis.

4. 2. 12 How Grounded Theory was Utilised in the Present Study

In the present study a modified grounded theory approach was adopted, so as to be pragmatic rather than purist, and one that resembled a mix of the descriptive and thematic along with central concepts from grounded theory.

In the next sections, stage one of the study is described including the study sample, ethical considerations, interview questions, data coding and analysis and a process that was used by the researcher to verify the study findings.

4. 3 Description of Stage One of the Present Study

Stage one of the present study consisted of interviews with seventeen husband-carers in their own homes who met the criteria for inclusion in the study. As the interviews progressed one of the participants requested to drop out, leaving sixteen data sets. The data for the husband who withdrew was not included in the analysed data. After several interviews, the combined data were analysed to identify themes, concepts and categories. The researcher stopped interviewing when no new information was forthcoming as recommended by Cutcliffe (2000).
According to Appleton (1995), disadvantages associated with interviewing include that it is costly and time consuming, for example, related to time taken travelling to interviews and transcribing and coding data or paying for the data to be transcribed. These drawbacks are balanced by participants being comfortable with stopping an interview or declining to answer particular questions, which they may not have been in researcher ‘territory’. The latter scenarios could raise ethical issues of informant disempowerment, which were avoided in this study as identified in Section 4.3.3.

4.3.1 Study Sample

The sample was a convenience sample of husbands who were the primary carers of wives at home who had been diagnosed as having dementia. Participants were almost entirely 60 years of age and over who had been providing care for their wives for twelve months or more. Participants from overseas had been living in Australia for at least five years and were able to converse and write in English. They were identified from four metropolitan Aged Care and Dementia Services in a large Australian city that the researcher had had contact with over several years. Potentially suitable participants for the study were identified by doctors, nurses and social workers from those services. They included both carers who were attending support groups and others who did not.
4.3.2 Ethical Considerations

Ethical approval for the research project was obtained from the ethics committees of all hospitals from whose services participants were identified, and the researcher’s University at the time. Staff of participating Aged Care and Dementia Services then contacted potential participants by phone to seek permission for the researcher to make phone contact, explain the study, what would be expected of them, answer any questions they might have, and to request their participation. All husbands who were contacted agreed to take part and an arrangement was made to conduct the interview in their homes. Participants were provided with an Information Sheet (see Appendix 1) and asked to sign the University Consent Form (Appendix Two). Interviewees were informed that they could withdraw from the study at any time after agreeing to take part and were assured that all interview data were confidential. No real names were used and tapes and transcripts were kept in a locked drawer within the researcher’s office. Interview transcripts were viewed only by the researcher and one or two by the researcher’s supervisor. Participants could not be identified from the transcripts by others as each was allocated a name that had no resemblance to their real one.

4.3.3 Interview Questions and Procedures

The literature review, discussions with the researcher’s supervisor, and findings from the researcher’s previous carer studies, enabled formation of semi-structured
questions to allow identification of pertinent data related to the research question. Questions were developed by the researcher that would not limit or bias the responses of the participants, assist them to feel comfortable in the interview and at the same time elicit a description of their care giving experiences. As suggested by Denzin & Lincoln (2000) questions were non-controversial, straightforward, and designed in such a way that would encourage husband-carers to elaborate on their experiences.

By prior arrangement with study participants interviews, lasting between sixty and ninety minutes, were conducted and audio-taped. Participants were assured of confidentiality and made aware of their right to stop or interrupt the interview at any time. The researcher sought to develop rapport with husbands by talking with them in general terms before more focused research questions were put to them.

The following questions were developed through which husbands were asked to describe their experience of caregiving:

1. How did you come to be looking after your wife? (Care giving history)
2. Can you tell me what it has been like to look after your wife? (Care giving experience)
3. How do you feel about your relationship with your wife now? (Relationship between care givers and wives)
4. What do you do for your wife? (Care giving practices and activities)
5. What help do you get from others? (Support for care giver)

6. What needs and problems do you have in relation to providing care?
   (Needs and problems associated with providing care)

These questions were not always asked sequentially although question 1. was often used as an opening question. Husbands’ responses determined whether all of the remaining questions needed to be asked and in what order as their responses might have covered the topic of interest during the course of the interview. In addition, demographic information that was collected for husbands and wives included age, country of birth, education (at school; after school) and main source of income. Other information was marital status, other residents residing in the home, employment status of husband, percentage of health costs related to wives’ illness, history and type of dementing illness.

4. 3. 4 Data Coding and Analysis

Participants’ descriptions of their care giving experiences were transcribed verbatim onto an A4 sheet of paper with an 80 column wide right-hand margin used by the researcher as a working area to summarise information, code data and identify and organise concepts. Accounts of husbands’ experiences were compared with each other. Labels were given to emerging themes. Data collection and analysis, literature reviews, and discussions with others occurred simultaneously, however, codes and categories by and large were derived solely
from the interview data. While husbands’ experiences are described fully in Chapter Five, two common themes were burden and depression. Concurrent literature reviews, discussions with the researcher’s supervisor, caregivers and health professionals, facilitated the testing and validation of these emerging themes.

**Validity of Findings in Qualitative Research**

Lack of strategies to determine the validity of findings in qualitative research has been of major concern to researchers and according to Burns & Grove (2005) researcher biases may go undetected. The authors describe strategies to examine the validity of findings from qualitative research, including obtaining feedback from informants. They suggest that study conclusions should be given to informants so as to obtain feedback about the accuracy of the information obtained as feedback and provides a ”different type of verification of the information” (p.384). The results chapter (Chapter Five), therefore, was sent out to six husband-carers, five of whom were not included in the study, a strategy suggested by Ezzy (2002, p. 68), to reflect on the accuracy of the findings and offer any comments about the portrayal of husbands’ care giving experiences and the derived models from stage one data analysis. Carers’ comments on the study findings are reported at the end of Chapter Five.

Further research questions and standardised measures of burden and depression
were identified for further exploration of husbands’ caregiving experiences in the stage two of the study. This allowed the development of a more complete understanding of the phenomenon of interest. Philosophical and methodological aspects of stage two, utilizing a positivist research paradigm are outlined below.

4.4 Positivist Research Paradigm

Polit et al. (2001) have proposed that positivist research has its origins in the ontological view that there exists an objective reality to discover and measure. The objective reality is seen as being driven by real natural causes or laws thus emphasising its rational and scientific origins (Polit & Beck, 2004). Quantitative research is closely allied with the positivist tradition. In quantitative research, the researcher employs a systematic approach by defining a problem, selecting concepts (known as variables) on which to focus, a study design and using scales or measures so as to generate numerical data. Selection of a random, probability, or non-probability sampling approach is also an important characteristic of such designs (Burns & Grove, 2005).

According to Schneider et al. (2004), quantitative research requires reduction and organisation of the data, application of statistical analysis, determination of significant relationships, and identification of differences between study groups, if more than one group is used. It can be used to study a wide range of problems
where measurement techniques can be applied and its use, in principle, increases
the generalisability of results to similar populations (Polit et al., 2001).

The researcher, working within this paradigm, seeks to understand particular
designated characteristics of phenomena that may be measured. For example,
determining whether Baroque Music significantly reduces nursing home
residents’ agitated behaviour associated with dementia. Rigour, using this
paradigm, is achieved by identifying systematic procedures to test ideas about the
phenomenon being studied, proposing theories or hypotheses to be tested, strict
adherence to the appropriate research design/s, and by employing appropriate
statistical analysis (Polit & Hungler, 1997). The end result should be to reduce
the effects of the researcher bias on study findings. Typically, when aspects of
human conduct are being quantitatively researched, they are referred to as
‘subjects’, emphasising the researcher’s objectivity or neutrality. However,
elsewhere, Polit & Beck, (2004) have argued that complete objectivity in
quantitative research is unachievable, even if all procedures to establish validity
have been utilized. Moreover, Burns & Grove (2005) note that positivistic inquiry
relies too strongly on rigorous techniques and numerical description, a narrow
definition of objectivity, and a prescriptive statistical model. However, according
to Schneider et al. (2004) the standards set by the Cochrane Collaboration
(www.cochrane.org) for the evaluation of statistical/quantitative studies through
rigorous systematic reviews of research on particular topics, have done much to
address quantitative research problems of poor design, inadequate sampling, faulty interpretation and over-enthusiastic or inaccurate claims of generalisability.

There are several common and broad types of quantitative research. Only the two types that were used in this study will now be described and their strengths and weaknesses highlighted. Stage two of the present study utilised descriptive quantitative and correlational research. Descriptive quantitative research provides a picture of an individual, group or situation of interest to the researcher. It describes a phenomenon, the frequency with which something occurs, and enables the researcher to develop categories from the information obtained, for example, the researcher may be interested in the gender of support group attendees and how many times they have attended a group. Descriptive research uses structured interviews, observations, and questionnaires to describe the phenomenon of interest, assisting the researcher to develop hypotheses to direct further quantitative research (Roberts & Taylor, 2002). Problems with this type of research include that (a) subjects, for example, carers who attend support groups, do not necessarily represent the population of interest (for example, all carers), as sampling error may have occurred and not been acknowledged, and (b) the setting in which the research occurs does not always allow the researcher to control the variables of interest (Crookes & Davies, 1998). The second type of quantitative research utilised was correlation research. Correlational research investigates the relationships between two or more variables. Relationships can be positive or negative; the strength of the relationship is also determined thus allowing the
researcher to explain the nature of the relationship (Polit et al., 2001). An example is where a researcher, interested in examining whether there is a relationship between levels of drinking and age, develops a study that examines if such a relationship exists. Findings might indicate that age and drinking are negatively correlated. It can be concluded that as the person ages, the level of drinking decreases. Weaknesses associated with this design include no researcher control over the study elements, or only partial researcher control of the setting and use of non-random or non-probability sampling.

4. 5 Stage Two of the Study

In stage two a descriptive, correlational design was used to examine male spouse care giving experiences. Four broad research questions were posed by the researcher to provide an adequate picture of the informants’ situation. These questions and related measurement scales, the questionnaire which was to address these, and the sample characteristics of participants, are fully described in the following pages.

4. 5. 1 Broad Research Questions.

There were three broad research questions that were developed for stage two of the present study from stage one findings, further reviews of the literature, discussions with service providers and family carers, and the researcher’s
1. Which husbands’ and wives’ characteristics are the best predictors of husbands?:
   a. sense of burden as measured by the Zarit Burden Scale (Zarit et al., 1986) (comprising 22 items)?
      (See Appendix Four)
   b. level of depression as measured by the Beck Depression Inventory (Beck et al., 1961) (comprising 21 items)? (See Appendix Five)

2. What is the effects of husbands’ general physical (Q16) and emotional health (Q17) on their burden and depression levels?

3. a) What supports do husbands utilise and what is their evaluation of them? (Qs48 to Q51); b) What is the impact of supports or lack of them on husbands’ i) burden and ii) depression?

4. 5. 2 Questionnaire and Measures Used in Stage Two

Questionnaire Items were derived from stage one findings, further readings of the literature, discussions with carers, staff of aged care and aged care psychiatry services staff, and the researcher’s supervisor. Some of the questionnaire items and standardised measures had been utilised by the researcher in various carers’ studies he had conducted since 1987. From stage one findings, it was evident that husbands were experiencing a sense of burden and some were also depressed. It
was also clear that some were utilising a model of care giving that was based on previous work experiences. Findings also highlighted that husbands utilised a range of coping strategies to assist them to manage what was becoming an increasingly difficult situation. For many there were a number of barriers that made care giving more difficult, including other responsibilities and having to undertake intimate care, for example, toileting wives, which was found to be distressing. The questionnaire items and measures identified were selected by the researcher after careful reflection in an attempt to quantify husbands’ experiences more fully, especially in relation to burden and depression. To this end, selected standardised measures of burden and depression were included to allow an examination of selected husbands’ and wives’ variables on these. Variables were associated with carer effort, perceptions of the role, effects of physical, emotional and relationship changes, carer personality traits, supports, carer upbringing experiences, other caregiving experiences and previous work experiences. In addition, open-ended questions allowed husbands to add any further information or elaborate on their responses to questionnaire items.

4. 5. 3 The Questionnaire

The questionnaire (Appendix Three) developed for Stage Two of the present study, was sourced in the following ways:
The University of Utah Questionnaire

- Items were included from a questionnaire developed by Dale and Lund, The University of Utah, Centre for Gerontology developed and provided by the authors to the present writer in 1987 to utilise in an Australian context, with the goal of sharing results with researchers at the Centre. At the time, it was adapted by the researcher as follows before use:

- A question about informants’ specific sources and amounts of income was omitted at the request of Alzheimer's Association (AA) of NSW, before the study was approved for research into experiences of caregivers who were attending groups facilitated by Alzheimer’s Disease and Related Disorders Society (ADARDS). The researcher complied with a recommendation by the Chair of the AA Ethics Committee that a substitute question be included about husbands’ and wives’ main source of income, including Age Pension and Superannuation, rather than the actual amount of income.

- Other inclusions, the Clinical Dementia Rating Scale (Berg, 1988), the Problem Behaviour Checklist (Zarit et al., 1980), and the Jallowiec Coping Strategies Scale (Jallowiec et al., 1984) were used at the suggestion of Dr. Henry Brodaty, Chairman, Alzheimer's Association, NSW.

In addition to those questions already noted, the following were included in a new questionnaire used in this study:
i) husbands’ religious affiliation (Q5) and importance of religious beliefs and practices (Q33), as some carers in Stage One had indicated the importance of these issues in relation to their care giving role.

ii) changes in feelings towards wives (Qs18 & 19)

iii) effects of upbringing experiences on the care giving role (Qs 34 and 35)

iv) reasons for taking on the care giver role (Q36)

v) effects of care giving on the husband-carer relationship (Qs 37 and 38)

vi) previous experiences providing care and extent to which these were helpful in the present care giving role (Qs 39 and 40)

vii) aspects of care giving the care giver liked/disliked (Q41)

viii) care giving perceived to be like previous job (Qs 42, 43 and 44)

ix) extent to which previous employment helped husbands carry out care giver role (Q 45)

At the suggestion of the researcher’s supervisor, space was provided at the end of each section of the questionnaire, so that husbands could provide any additional information or comments related to the responses to the questionnaire items in sections A, B, C, D, and E. A request to that effect, was placed at the end of each section.
Questionnaire items were organised by the researcher under section headings that reflected the content of the questions:

1. For Husbands
   A. Biographical information (Qs 1-11)
   B. Care giving responsibilities (Qs 12-28)
   C. Care giver support (Qs 29-33)
   D. Care giver role (Qs 34-47)
   E. Community supports and services (Qs 48-51)

Measures included:

i. Zarit Burden Scale (Zarit et al., 1986) (Appendix Four)

ii. Beck Depression Inventory (Beck et al., 1961) (Appendix Five)

iii. Jaloweic Coping Strategies (Jaloweic et al., 1984) (Appendix Six)

iv. Sex Role Index (Bem, 1974) (Appendix Seven)

v. Barriers to Caregiving Index (Kaye & Applegate, 1990a.) (Appendix Eight)

2. For Wives
   A. Biographical profile (Qs 52-63)

Measures included

vi. Clinical Dementia Rating Scale (Berg, 1988) (Appendix Nine)

vii. Problem Behaviour Checklist (Zarit et. 1980) (Appendix Ten)
Husbands were asked to answer all questions and complete all measures to the best of their ability. As there was a lot of paperwork involved they were encouraged to take their time completing the questionnaire and measures.

4. 5. 4 Measures of Husbands’ Experiences

The following measures were used to examine the variables of interest in this stage of the study:

1) Husbands’ sense of well being (Zarit Burden Scale – Zarit et al., 1986; and Beck Depression Inventory) (Beck et al., 1961)
2) Wives’ condition (Problem Behaviours Checklist (Zarit et al., 1980) and Clinical Dementia Rating Scale) (Berg, 1988)
3) Husbands’ coping strategies (Jaloweic Coping Strategies) (Jaloweic et al., 1984)
4) Husbands’ personality traits (BEM’s Sex Role Inventory) (Bem, 1974)
5) Barriers to care giving (Barriers to Caregiving Index) (Kaye & Applegate, 1990a.)

As highlighted earlier, the writer had utilised four of the measures (Zarit Burden Scale (Zarit et al., 1986), Beck Depression Inventory (Beck et al., 1961), Jaloweic Coping Strategies Scale (Jaloweic et al., 1984), Clinical Dementia Rating Scale) (Berg, 1988) in several carer studies since 1987. For stage two of the present study, BEM’s Sex Role Inventory (Bem, 1974), Barriers to Caregiving Index
(Kaye & Applegate, 1990a.) and Problem Behaviour Checklist (Zarit et al., 1980) were added to examine the impact of additional carers’ and wives’ characteristics on husbands’ burden and depression scores. Measures used to explore husbands’ responses to care giving will now be discussed. Measures relative to wives’ condition will be outlined in the section following this.

**Zarit Burden Scale (ZBS)**

The ZBS, developed by Zarit et al. (1986) (Appendix Four), was designed to assess the degree of burden felt by care givers of dementia patients (Kahan, Kemp, Staples, & Brummel-Smith, 1985). The underlying assumption of this instrument is that the level of burden experienced by care givers is primarily the result of their role as care giver (Parsons, 1997). In this study, the 22-item measure developed by Zarit, Reever & Bach-Peterson (1980) was utilised to examine husbands’ level of burden. The minimum score for the total scale score is 22 and the maximum 110 (minimum score for each item is 1 and 5 for maximum score). Higher scores indicate a greater sense of burden. Reliability estimates for the scale in the literature have ranged from 0.71 to 0.91. In the present study, the internal reliability of the Zarit Burden Scale (Zarit et al. (1986) was high with a Chronbach alpha of 0.88.

The purpose of including this measure was to describe husband-carers’ burden levels so as to contribute to existing knowledge of how care giving impacts on
husband-carers and to identify those who may be ‘at risk’ and in need of early intervention by health services. In addition, the aim was to identify those independent variables from the developed questionnaire which predicted husbands’ burden levels.

The use of the ZBS, however, is not without its problems. For example, measures of caregiver burden as a total scale score may mask dimension-specific patterns of caregiving impact and which variables individually or in combination, would predict burden (George & Gwyther, 1986).

**Beck Depression Inventory (BDI)**

The BDI measures the presence of clinical depression and allows a quantitative assessment of the intensity of the depression. Burns, Lawlor & Craig (1999, p.6) state that it “represents the gold standard for self-rating depression rating scales and is often used in assessing depression in carers of patients with dementia”. It is a 21 item self-report rating inventory (Appendix Five), developed by Beck et al., 1961, which measures characteristic attitudes and symptoms of depression (Stinton, 2003). Each item describes a specific manifestation of depression (cognitive, behavioural, or vegetative). There are four response choices for each category or series of statements rated 0,1,2 and 3 (minimum score is 0, maximum is 63) denoting increasing severity of symptoms. Respondents indicate which is most accurate for the past week, including the day on which the measure was
completed. The BDI takes approximately 10 minutes to complete. A fifth or sixth grade reading age is required to adequately answer the questions (Stinton, 2003).

Questions are asked about feelings of sadness, concerns about the future, suicidal ideation, tearfulness, sleep, fatigue, interests, worries about health, sexual interest, appetite, weight loss and general enjoyment. Greater depression is indicated by higher scores. The following score ranges are used as guidelines:

- 0-9 Normal Range
- 10-15 Mild Depression
- 16-19 Mild-Moderate Depression
- 20-29 Moderate-Severe Depression
- 30-63 Severe Depression

From the literature review in Chapter Three we know, in general terms, that caregivers in similar contexts have been found to experience high levels of depression. However, we know little of husbands’ care giving experiences in an Australian context and whether these experiences cause some husbands to become depressed. Depression is treatable and therefore it is important to recognise it early (Alexopoulos, Borson, Cuthbert, Devanand, Mulsant, Olin & Oslin, 2002).

The BDI has been found to have adequate reliability and concurrent validity when used in studies which included older participants. A meta-analysis of the BDI’s
internal consistency estimates range from 0.73 to 0.92 (Stinton, 2003). It has been used by this researcher in carers’ studies since 1987. The internal reliability of the Beck Depression Inventory (Beck et al., 1961) in Stage Two of the present study was moderately high with a Chronbach alpha of 0.76.

**Jalowiec Coping Scale (JCS)**

At the time of the study, little was known about the coping strategies of husbands who were providing care. The purpose of including the JCS (Appendix Six) was to identify husbands’ coping strategies and examine the effects of these on husbands’ burden and depression levels. The scale consists of 40 coping behaviours which are rated on a 1 to 5 scale to indicate degree of use and was developed by Jaloweic et al., 1984). It is designed to assess how often a respondent engages in particular coping behaviours (Burke, Lund, Hill, Packard, Kondo & Bluhm, 1990). Burke et al. have identified through factor analysis the following sub-types of coping strategies within the scale: 1) problem-solving (Items 1-5, 7-10, 13-15, 22, 23, 29), 2) avoidance-evasive (Items 11, 12, 17, 21, 25, 28, 33-36, 39), 3) reframing (Items 16, 18-20, 26, 27, 30, 38) and 4) regression (Items 6, 24, 31, 32, 37, 40). These sub-groups were used elsewhere by the present writer (Brown et al., 1995) to analyse the data obtained in their study of carers. In the present study each of these sub-types were regressed on husbands’ burden and depression levels.
Evaluation of the scale by others has yielded rank-ordered correlation coefficients (rhos) of 0.78 to 0.86 (Jaloweic, Murphy & Powers, 1984). In the present study internal reliability of the scale was moderately high with a Chronbach alpha of 0.76, however, internal reliability for the sub-scales varied considerably as follows: avoidant-evasive strategies (0.71), regressive strategies (0.39), problem-solving strategies (0.77) and reframing strategies (0.57). This finding, and its implication for study findings, will be discussed in Chapter Eight.

**Sex Role Index (SRI)**

Gender has been shown to act as a stressor and therefore, in the context of male care-giving, may constitute a barrier to it (Lindquist & Sjoden, 1998). For example, Zarit, Todd & Zarit (1986) found that husbands as care givers were more likely to have problems assuming household responsibilities. One of the objectives of the present study, therefore, was to examine the effects of gender on husbands’ burden and depression levels.

The original measure developed by BEM comprised a 20-item scale (Bem, 1974; Edley & Wetherell, 1995). The index utilised here (the 10-item measure; see Appendix Seven) represents a modified and shortened version of the original sex-role inventory. It gauges the extent to which individuals perceive themselves to exhibit traditional male (‘instrumental’) as compared to female (‘affective’) personality traits (Kramer & Thompson, 2005). The 10-item composite measure
is scored on a 5-point scale where 1 = rarely or never, 2 = sometimes, 3 = often, 4 = usually, and 5 = almost always. The items in the index for instrumental orientation are aggressive, analytical, forceful, competitive and self-sufficient. Remaining items relate to affective orientation and include loving, compassionate, yielding, gentle and warm.

Kaye & Applegate (1990b.) in two of their studies have reported the reliability coefficient for the 10-item SRI to be 0.71 and 0.68. In the present study, internal reliability of the scale was 0.46 for instrumental traits (if “Aggressive” is removed, it becomes 0.53), and 0.77 for affective traits. This finding, and its implications, will be discussed in Chapter Eight.

Barriers to Caregiving Index (BCI)

The BCI, developed by Kaye & Applegate (1990a.), allows researchers to determine the extent to which individual variables act as barriers to care giving and impact on carers’ experiences of burden and depression. Specifically, the index gauges the extent to which a range of potential factors serve to limit the amount of care men provide to their relatives or friends. The BCI is a 16-item index (Appendix Eight) which is scored on a 4-point scale where 0 = not at all, 1 = minimally, 2 = to some degree, and 3 = very much so. The items included in the index are the requirements of the carers’ job, family obligations, the nature of their social life, their opinion and those of others as to what appropriate behaviour
for men should be, quality of their past relations with relative/friend, the general stress associated with care giving, the distance the carer lives from the relative/friend, the availability of other relatives and friends who can provide help, carers’ general health, the physical health of carers’ relative/friend, the mental or emotional health of the carers’ relative/friend, the general personality of relative/friend, the sex of relative/friend, carers’ family’s tradition of helping others, and the availability of community services for relative/friend.

In Kaye & Applegate’s study (1990b.) of male caregivers, the reliability coefficient for the BCI was 0.86 and in the present study 0.79.

4. 5. 5 Dependent Variables: For Wives

Measures of wives’ condition comprised the Clinical Dementia Rating Scale (Berg, 1988) and the Problem Behaviour Checklist (Zarit et al., 1980). The aim of including these measures was to examine (1) the extent to which the illness had progressed, (2) the extent to which behavioural problems associated with the illness were present, and (3) the effects of wives’ disabilities on husbands’ experiences of burden and depression in an Australian context. Each measure will be described in more detail.
Clinical Dementia Rating Scale (CDRS)

Severe memory loss and the problems associated with dementia are distressing to family members. There is earlier evidence in the literature that suggests that caregivers’ burden is strongly related to care receivers’ disabilities (Zarit et al., 1986) although Zarit et al. (1980) have demonstrated that this is not always the case.

The CDRS (Appendix Nine), developed by Berg (1988) has been described as a comprehensive rating scale in which performance is rated in six domains as follows: memory, orientation, judgment, problem-solving, community activities, and personal care (Burns & Hope, 2004). It uses a 5-point scale: 0=no impairment, 0.5=questionable, 1=mild, 2=moderate, and 3=severe and assesses dementia severity by staging. It can also be used as a diagnostic tool (Patterson et al., 1998). The CDRS has been found to have good inter-rater reliability (r=0.89, by Hughes, Berg, Danziger, Cohen & Martin, 1982) and has been described by Burns et al. (1999) as one of the gold standards of global ratings of dementia in patients with Alzheimer’s disease. In the present study internal reliability of the scale was 0.82.

Normally, in the clinical setting the patient’s doctor or a nurse would complete the CDRS based on an interview with the patient. In the present study, husbands
completed the scale based on their day to day knowledge of their wives’
behaviour.

Problem Behaviour Checklist (PBCL)

Previous research on elderly people with impairment has indicated that specific
problem behaviours, for example, wandering and insomnia (Zarit et al., 1980;
Zarit et al., 1986) are burdensome to family members. The PBCL (Appendix
Ten) is a 30-item checklist of care receivers’ problem behaviours as reported by
care givers. Reliability and validity studies of the instrument have not been
reported. Brodaty & Hadzi-Pavlovic (1990), however, have reported high internal
consistency between the items in their samples but did not specify what they were.
In the present study internal reliability for the scale was 0.77.

In summary, the chapter so far has described the development of the methodology
utilised in stage one of the study. Stage one utilised grounded theory
methodology, informed by a Symbolic Interactionist perspective and content
analysis to identify themes and patterns from participant interviews. In stage two,
a descriptive and correlational design was used to examine male spouses’ care
giving experiences utilising a comprehensive questionnaire and standardised
measures described earlier in this chapter. The following paragraphs describe the
sampling procedures in stage two of the study including eligibility criteria for
inclusion, sample sources and response rate; as well as data analysis.
4. 5. 6 Stage Two Sampling Procedures

One hundred and eighteen questionnaires were sent out to both metropolitan and rural carers who met the criteria for inclusion in the study. Selection criteria required that husbands were primary carers of wives who had been formally diagnosed as having dementia, 60 years of age or over, and able to complete questionnaires and standardised measures independent of the researcher’s presence.

Names of potential participants were obtained from the Carers’ Association of New South Wales, Alzheimer’s Association, Aged Care Services, Concord Hospital, Hevington House, Auburn (Day Care Centre), Parramatta Community Options, members of the NSW Psychogeriatric Nurses’ Association, Lidcombe Hospital, Aged Care Psychiatry Service, Central Coast Area Health Service, and carers identified by other carers interviewed in stage one of the study. Sample two, therefore, was referred from multiple service providers and thus study participants cannot be seen as representative of the population.

Seventy-one carers returned the questionnaire with all questions completed. This represented a response rate of 60%. The researcher’s supervisor at the time, who had conducted several care givers’ studies, highlighted that this was a quite a good response rate for this group of informants. Of these participants, 29 (41%) of the respondents were from rural areas of New South Wales and 42 (59%) from the
The following section describes the procedures and rationales used to analyse statistical data derived from stage two of this study.

4.5.7 Analytical Procedures and Sample Size

Decisions were made by the researcher after discussion with his supervisor in relation to the type of analysis which would be appropriate, given the number of variables and the sample size, the cut off threshold for condition index (CI) and variance inflation factor (VIF) values. A VIF over 10 and a CI over 30 represents a high degree of collinearity (Dupont, 2002), that is, that a significant independent variable is explained by another or other independent variables in the analysis. These concepts are further explained in section 4.5.8.

Multiple regression is a method of analysing the collective and separate contributions of two or more independent variables to the variation of a dependent variable (Hair, Anderson, Tatham & Black, 1995; Minichiello et al., 2004). According to Burns & Grove (2005), its focus is predictive rather than aimed at determining the differences in groups. However, Polit & Beck (2004) state that it is also useful to ask inferential questions about relationships in the regression analysis to enable the researcher to determine if the calculated $R$ is the result of true relationships or due to chance. Another advantage is that it allows all
variables, whether categorical or continuous, to be used in attempts to explain the dependent variable (Polit & Beck, 2004). As there were a large number of variables of interest to the researcher in examining their effects on husbands’ burden and depression, the variables were grouped into eight clusters to reduce Type I errors (Collins & Jones, 1995). Clusters comprised between four and nine variables. Cluster One to Seven comprised husbands’ characteristics of interest and Cluster Eight related to wives’ characteristics of interest (see Table 4.1). Specifically, the researcher examined the effects of each of the variables in each of the clusters (the independent or predictor variables) regressed on husbands’ burden and depression scores (the dependent variables) so as to predict the changes in the dependent variables in response to changes in the independent variables using stepwise regression (see Howell, 1997).

The eight clusters of variables were given a descriptive title that matched their content (see Table 4.1).
**Table 4.1**

**Cluster Variables**

<table>
<thead>
<tr>
<th>Cluster Variable</th>
<th>Descriptive Title</th>
<th>Question Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cluster One</strong></td>
<td><strong>Husbands’ demographics</strong></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>Q1</td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td>Q2</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td>Q4</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td>Q5</td>
</tr>
<tr>
<td>Main source of income</td>
<td></td>
<td>Q11</td>
</tr>
<tr>
<td>Place of residence</td>
<td>*</td>
<td></td>
</tr>
</tbody>
</table>

Wives’ demographic variables

| Age              | Q52              |
| Country of birth | Q53              |
| Highest level of education | Q54  |
| Main source of income | Q56  |
| **Cluster Two**  | **Characteristics of care giver effort** |   |
| Percentage of health care costs |                   | Q12 |
| Percentage of care giver responsibility |               | Q13  |
| Hours in direct & indirect care |                   | Q14 |
| Length of time providing care |                   | Q15 |
| **Cluster Three** | **Carers’ Perceptions of their Role** |   |
| Care giving seen as being like a job |                   | Q42 |
| Care giving seen as being like job used to do |   | Q43  |
| Relevance of experiences in previous job to present role | Q44  |
| Importance of being organized & efficient |                   | Q46  |
| Care giving seen as being important |                   | Q47  |
| **Cluster Four**  | **Effects of Care giving on Husbands** |   |
| Closeness of emotional relationship with impaired spouse |                   | Q6  |
| Changes in husbands’ physical health status |                   | Q16 |
| Changes in husbands’ emotional health status |                   | Q17 |
| Changes in husbands’ feelings towards spouse |                   | Q18  |
| Effects of care giving on relationship |                   | Q37  |
| **Cluster Five**  | **Influences on Husbands’ Role as Care giver** |   |
| Extent to which upbringing prepared husbands for care giving role |                   | Q34  |
| Extent to which previous care giving experiences prepared husbands for care giving role | Q35  |
| Personality traits | Bem Sex Role Inventory |
| Coping strategies | Jalowiec Coping Strategies Scale |
| Experiences in previous job |                   | Q45 |
| **Cluster Six**  | **Supports: Relatives & Friends, & Religious Beliefs & Practices** |   |
| Ease of contact |                   | Q30  |
| Number of friends providing support |                   | Q29  |
| Other household residents |                   | Q7    |
| Specific person to share with |                   | Q31  |
| Religious beliefs & practices |                   | Q33  |
Cluster Seven | Supports: Support Group Attendance
--- | ---
Attending support group | Q21
Support group met expectations | Q26
Number of group meetings attended | Q25
How helpful group was emotionally | Q23
How helpful group was providing information | Q22
Relatives & friends attending group | Q24

Cluster Eight | Characteristics of Wives’ Condition
--- | ---
Length of time changes recognized by husbands | Q59
Problem behaviours | Problem Behaviour Checklist
Severity of illness | Clinical Dementia Rating Scale
Length of time since diagnosis | Q61
Course of wives’ illness | Q63

* Husbands’ place of residence wasn’t a questionnaire item but this information was available from a master record kept by the researcher for all participants.

4.5.8 Normality and Multicollinearity

Before the analysis was performed, the data were examined for normality and multicollinearity so that significant variables that might be explained by another or other independent variables could be excluded from the findings. Both of these conditions are underlying assumptions of multiple regression analyses. Normality refers to the shape of the data distribution for an individual variable and the way in which it corresponds to the normal distribution (Hair et al., 1995). The normal distribution makes a straight diagonal line, and the plotted data values are compared with the diagonal. If the variation is sufficiently large, all resulting statistical tests are considered invalid (Dupont, 2002). Normality is evaluated by checking the histograms and enables the researcher to compare the observed data values with a distribution approximating the normal distribution methods (Tabachnick & Fidell, 1996). However, this method becomes problematic for smaller samples as the histogram can distort the visual portrayal. In the present study, the distribution of data values for statistically significant variables from
each cluster was plotted by the researcher. Results indicated that the lines representing the data distribution followed the diagonals reasonably closely.

Multicollinearity refers to the correlation among several independent variables and becomes an issue when one is regressed against the others (Tabachnick & Fidell, 1996). Multicollinearity reduces a variable’s predictive power by the extent to which it is associated with the other independent variables (Dupont, 2002). In the present study, the VIF was calculated to assess multicollinearity or the degree to which each independent variable was explained by the other independent variables. The cut off threshold for the VIF values is over 10. In addition, the CI (which represents the collinearity of combinations of variables in the data) was examined to measure the relative amount of variance associated with an *eigenvalue*. A large CI, that is, an index greater than 30 indicates a high degree of collinearity (Hair et al., 1995). In the present study, where correlations produced VIFs over 10 and CI’s over 30, they were omitted from the reported findings as detailed in Chapter Seven.

4.5.9 Stepwise Regression

According to Tabachnick & Fidell (1996), statistical regression is a rather controversial procedure in which order of entry of variables and which variables to include is based solely on statistical criteria, rather than theoretical criteria. There are three versions of statistical regression: forward, backward and stepwise
(Howell, 1997). In forward selection, the equation starts out empty and independent variables are added one at a time provided they meet the statistical criteria for entry. In backward selection, the equation starts out with all independent variables and they are deleted one at a time if they do not contribute significantly to regression. Minichiello et al. (2004) report that stepwise regression is a compromise between the other two procedures in which the equation starts out empty and independent variables are added one at a time if they meet statistical criteria, but they may also be deleted at any step where they no longer contribute significantly to regression.

In the present study the stepwise regression method was utilised to identify the variables in each cluster which were significantly correlated with husbands’ burden and depression scores. This enabled the researcher to select from a group of independent variables, the variable or variables that made the largest contribution to $R^2$ (Polit & Hungler, 2001). The $R^2$ statistic is designed to indicate to the researcher and to other readers the proportion of variation explained by the model derived from the regression analysis (Minichiello et al., 2004). In addition, the identified significant demographic variables for burden and depression were entered into the equation as moderator variables for each cluster, as the researcher was interested in identifying the unique contribution of the significant cluster variables to the variance of burden and depression over and above these demographic variables. Finally, each of the significant variables, so identified from regressing each cluster variable on the dependent variables, was then entered
into a regression equation to determine the contribution of each to the variance of burden and depression when compared to each other.

4.6 Summary

This thesis explores the experience of husbands who were caring in their homes for their wives who had been diagnosed as having dementia. This chapter has described how the study was developed and carried out. First, in Stage One of the study a qualitative research paradigm was employed as an appropriate method to study husbands’ care giving experiences. Stage one utilised grounded theory from a Symbolic Interactionist perspective. Grounded theory guides the systematic and rigorous collection, coding of data and identification of important themes. It was through these processes that emerging theories explaining older husbands’ care giving experiences was developed. These are described and examined in the next chapter.
CHAPTER FIVE

RESULTS FROM STAGE ONE OF THE STUDY

Models of Husbands’ Care giving Experiences

In Stage One of the present study the care giving experiences of sixteen husbands providing care for wives with dementia at home were explored. Husbands were invited to reflect on how they came to be providing care and their present and future experiences. From the data, husbands’ psychological distress was seen to be related to the tension created by their inability to meet their own basic needs due to having to manage their wives’ problem behaviours. Models of males’ care giving in the Past, Present, Future and Over Time are described in this chapter..

Introduction

This study examined the experiences of older husbands who were providing care for wives at home who had been diagnosed as having dementia. The study comprised two stages. In stage one, seventeen husbands were identified by the researcher through discussions with service providers and others within the Sydney metropolitan area and after giving informed consent to participate in the study, all seventeen interviews were completed by the researcher in participants’ own homes. Of these, one requested to drop out of the study after the interview and the information from this was not included in the analysis that follows. During the interview, the researcher used open-ended questions to explore husbands’ experiences as care givers. Interviews were taped and transcribed
Interview data were analysed using grounded theory and content analysis to identify themes that captured husbands’ experiences. Three models of care giving were identified relating to the Past, Present and Future. An overall model incorporating husbands’ experiences over time was also developed from the data.

This chapter describes the experiences of husbands as care givers. During the interviews husbands focused on six interview questions (see Chapter Four): (1) their understandings of the beginning of their wives’ problems and how they came to be providing care (2) their reactions to the care giving role (3) the effects of care giving on the husband-wife relationship (4) care giving activities and practices; (5) the assistance and support they received from others; and (6) their needs and problems associated with providing care. The first interview question related to the past, the second to the past and present, interview questions 3, 4 and 5 related to the present, while interview question six to the present and future. Clearly, however, husbands were only able to reflect on their past and possible future experiences from the standpoint of the ‘the present’, a concept known as temporality.

5.1 Temporality

Whilst the following data are organized by the researcher in this chapter in terms of husbands’ past, present and future understandings of their experiences, Ezzy
(1998) has proposed that each of us interprets our past in relation to present or future projects and goals in the present to enable a coherent sense of self to be created and sustained, and through this process any discontinuity of the present and past is resolved (Ezzy, 2002), the process is known as temporality. Temporality also facilitates an ordered interpretation of what the past was like (for example, when care giving began), helps determine the meaning of present care giving experiences, and assists with ideas about what the future will be like (for example, carers’ perceptions of their future circumstances), thus providing a focus for future action (Perinbanayagam, 1987).

Clearly, from the data, events happened to husbands in the past, for example, husbands noticed that wives experienced changes in behaviour, they interpreted what these meant and made adjustments for them. When wives were diagnosed as having dementia, they gradually accommodated to the situation in ways which were characteristic of them as individuals so as to be able to provide increasing amounts of care. Through telling their stories, the past became symbolically constructed by them in the present through memory images (Ezzy, 2002), as they reflected with the researcher on their care giving experiences over time. Through this process, events that would normally appear discordant to husbands (for example, care giving itself was a new experience for them), were integrated and sense made of these events in the narratives they created. Thus a sense of identity was able to be constructed by husbands - that of carer - so that the remembered events and perceptions of their past, present and future became part of their life
story (Ezzy, 1998), with the future, however, existing only as alternative possibilities. This process necessarily involves a complex moving back and forth between events through some sort of internal dialogue and interactions with others and even the researcher, so as to create a coherent whole.

Husbands’ care giving experiences will now be described including their reflections on the past, perceptions of present experiences and thoughts about the future. Models of husbands’ care giving are described for each and an overall model of husbands’ care giving over time is proposed although this will be described first to provide an overview of what follows in the other models.

Each of the diagrams (Figures 5.1 through 5.4) that are presented in this chapter depicts the perceptions and responses of husbands to wives’ behaviours associated with dementia and their own care giving experiences. As these experiences intensified, husbands were deprived of personal time and space and work and social activities were compromised. As problems became more prominent husbands increasingly explored a range of available support services which were helpful to some, but not all, of those interviewed. As the condition of their wives deteriorated, exasperation at having to meet their wives’ needs and at the same time deny their own, frequently led into a cycle of burden and depression. Figure 5.1 prefigures the other models and provides an overview of husbands’ experiences over time incorporating models of husbands’ care giving experiences related to the past, present and future.
Figure 5.1

Husbands’ Model of Care giving over Time

The above model depicts the main themes of husbands’ care giving related to the past, present and future. Model one (Figure 5.2 Husbands’ care giving related to the past, see p. 220), highlights the onset of wives’ problems related to dementia. Paralleling this is husbands’ decision to provide care. It identifies that care giving at first didn’t necessarily lead to a sense of burden or depression as husbands almost subtlety took over wives’ responsibilities and continued at the same time with their own. Most husbands for some time were able to meet their own basic needs.

In model two (Figure 5.2, p. 245) husbands’ care giving experiences related to the present are depicted and highlight the progressive nature of their wives’ illness
and related problems and increasingly how they were called upon to provide supervision. This gradually reduced their ability to meet their own needs leading to the development of a state of tension characterised by a sense of burden and some became depressed.

In model three (Figure 5.3 p.245), husbands perceived that their wives’ behaviour would become quite disabling and doubted their own abilities to continue providing care as they contemplated the now fearful future.

5. 2 The Past: Deciding to Care

The first interview question asked husbands to describe how they came to be looking after their wives. In response to this question, husbands described the changes that had occurred in wives’ behaviour, their interpretations of what these changes meant and their reactions to their wives being diagnosed with dementia. They also identified why they became carers. In relation to the Past, the main theme was *Deciding to Care*. The decision to provide care initially, and for many husbands, was not a significant problem since changes in wives’ behaviour was manageable and husbands were able to take over their wives’ roles gradually while maintaining their own responsibilities. For each husband but at different times, wives had been diagnosed as having dementia and wives’ behavioural problems related to this disorder, had increased over time. Thus, husbands found themselves taking over more and more responsibilities, making it increasingly
difficult to satisfy their own basic needs.

At some stage in the past each husband made a decision that he would provide care for his wife who had been diagnosed with a dementing illness and who was to varying degrees affected by it. Husbands gave a variety of reasons for this decision but basically there were three main reasons identified from the data. These were related to their marriage vows ‘for better or worse’, ‘giving back’, and ‘the love game’. Almost half of the husbands in the study reported that they had promised as part of their marriage vows to look after each other; or used the terms for better or worse. For example, Oswald stated Well, that’s what you do. I mean you’re married, you know, for better or worse. Similarly, in the words of Jack, who had been married for 52 years, See, when you get married, you marry for better and worse in sickness and health don’t you? Husbands also reported that they were providing care as a form of repayment or ‘pay back’ for all that their wives had done for them over their married life. As stated by Peter ... she has done so much for me and the family and I feel...I owe it to her ... She’s looked after me like a baby all my life ...

Other husbands highlighted that they were reluctant to place wives in an institution, that wives felt more secure at home and that care giving was motivated by love for their wives. Several husbands reported that they were reluctant to ‘put their wives away’, for example, into a nursing home. Adam stated I don’t want to put her away...even though ... everyone tells me now, keep going [on] at me ...
You must put her name down for a nursing home ... But I can’t. Several husbands made comments that suggested that they believed that their wives felt more secure in their own home, presumably with someone they knew rather than in an unfamiliar environment such as a nursing home with residents and staff who were strangers to their wives and themselves. Several husbands described that their care giving was motivated by their love for their wives. Jack stated ... well naturally you like to look after your loved ones. Similarly, Neville expressed his motive for providing care rather poignantly when he attributed it to being all tied up … in the love game.

Subsumed within this main theme - Deciding to Care - were four sub-themes, the first was Something’s not quite right.

5.2.1. Something’s Not Quite Right

The first sub-theme highlighted that husbands had noticed changes in their wives’ behaviour and that these changes had been recognized between one and 14 years ago prior to the time of interview and well before a diagnosis had been made. Consequently, many husbands had begun providing varying degrees of care for some considerable time. Changes identified indicated to them that something wasn’t quite right and changes to various aspects of wives’ behaviour were highlighted. Specifically, wives had become increasingly forgetful, had developed fears and worries, become inappropriate socially and increasingly
confused.

Alterations in wives’ memory, sometimes described by husbands as *forgetfulness or failure to remember*, were consistently identified by all husbands. Specifically, wives forgot where they had put things; information they had been given or had known; and to do things. Husbands reported that wives forgot where they had put things. They related, for instance, that wives had placed money or jewellery somewhere in the house other than where it was normally kept and then accused others of stealing objects that had in fact been mislaid. Other husbands also identified that wives forgot information that they had been given or had previously known. For Ian, a 70 year old carer, this became obvious when they were on an overseas trip. His wife, who was later diagnosed with dementia …

couldn’t remember what floor they were on in the hotel nor the room number….

Mark, 76 years of age, related that his wife ... *would have people ringing up to invite her to lunch and she would forget to put it in her diary*. Several husbands identified that wives forgot to do various things, including failure to complete all steps comprising a particular behaviour. For example, Larry, a retired doctor, noted how he first noticed his wife’s forgetfulness when she ... *left [a significant] ingredient out of a recipe* [when she was cooking] and when she *placed a chicken in the oven to cook still wrapped in plastic*.

Whilst memory changes were a prominent feature at the beginning of the illness and caused some inconvenience, from the data it seemed clear that these were
being well managed by most husbands at the time.

In addition to memory changes, several husbands reported that wives experienced changes in their emotions such as developing specific fears and becoming worried. Barry, a 71 year old husband whose wife had been diagnosed with dementia two years prior to the interview, remarked, for example, that his wife had developed a... *fear of aeroplanes, helicopters and police.* Fear of police might have had some basis in reality as she had been caught ... *shoplifting three times*... . These episodes might also indicate that her judgment was becoming impaired. Jack, at 86 years of age and the oldest carer in the study, related that his wife had a *fear of*... *being left alone* and another reported that his wife was... *worried about money.*

Husbands revealed that wives had become aggressive, did inappropriate things, lost interest in things that once held their interest and made unfounded accusations. Several husbands reported that their wives had become aggressive. Jack remarked that his wife’s aggression was... *uncharacteristic*... of her and he associated this behaviour with frustration related to her memory loss or that she thought that he was a stranger. Barry identified that his wife... *seemed to do silly things*... *she got undressed and went sunbaking on a brick balcony facing the road and a four storey building opposite where builders were working and could see her.* Graham, 71 years of age, who had been providing care for six years, described noticing that a... *few things*... *weren’t adding up ... she had no interest in*
anything whatever…, for example, he …went and bought a very expensive tennis racquet for her [she had played tennis for years] … she used it twice and then she didn’t go [anymore]…. His conclusion was that…perhaps the problems were already present… it wasn’t until after [he] retired and was home all day each day…that the problems became more apparent. Ian, a 70 year old husband, related that during an overseas trip he was taking pictures of other members in the party and his wife accused him of…playing up with another woman in the party.

Several husbands reported that early in the illness wives had become confused about where they and others were, and where objects belonged. One husband, for example, described that whilst they were on an overseas trip his wife wanted to know where George [her son back in Australia] was going to sleep? He also illustrated that at another time…when they went out shopping and bought, say fruit…she said ‘Where does this go?’…’In the fruit dish I told her’. Frank, a 72 year old husband, related similar changes in his wife’s orientation. In his words …she used to go shopping with a friend of ours and she’d say ‘Where are we?’

In summary, it may be noted that the extent to which changes had occurred in wives’ behaviour varied from wife to wife and included changes in memory, emotions, behaviour and orientation, however, the most commonly reported change was memory loss sometimes referred to by husbands as forgetfulness. Changes were variously interpreted by husbands and involved a range of reactions and interpretations that will be discussed in the next section.
5. 2. 2 Transition to Carer

The second sub-theme was described by the researcher as *Transition to Carer*. All wives had been diagnosed as having Alzheimer’s disease as described in Chapter Two. Diagnoses had been made between one and over 14 years ago prior to the time of interview. However, as noted in the previous section, the length of time that changes in wives’ behaviour had been noted by husbands to be present was much longer than 14 years and they had been providing care, therefore, for much longer than the date of diagnosis indicates.

The transition to carer was not the result of a decision that was made at a particular point in time, but, represented a shift in what husbands were already doing in terms of care provision to providing increasing levels of care for their wives. Care giving activities, and the amount of time devoted to them therefore, increased over time as their wives’ behaviour deteriorated further. At the time the interviews were conducted most husbands were providing full time care.

Most husbands (94%) were retired when changes in wives’ behaviour began although two were still working. Quentin, for example, continued to work full time and provided part-time care. Eventually, he had to give up work to provide full time care as his wife’s condition worsened. Changes in wives’ behaviour meant that husbands had to change their role as retiree to that of carer. As problems increased, husbands assumed more and more responsibility for their
wives and continued to do what they had been doing all along as well, for example, home and car maintenance. Some husbands described the transition to carer as being not too difficult. Several husbands described that it was a natural thing to provide care for their wives as they had been involved in other care giving activities throughout their lives, for example, assisting with care of children as they were growing up.

5. 2. 3 What’s It All Mean?

The third sub-theme from the data, highlighted that husbands had reached various conclusions about the meaning and significance of changes in their wives’ behaviour. Some recognised that there was something profoundly wrong but didn’t know what it was; others that changes had occurred and described these to their doctor who diagnosed dementia. Several husbands were suspicious that it was Alzheimer’s disease. A few had suspected that their wives had developed dementia but refused to accept the diagnosis.

Several husbands reported knowing something was seriously wrong with their wives but didn’t know exactly what it was. Barry, for example, stated that he had…noticed that something wasn’t quite right…noticed that something was definitely off … but, hadn’t heard of Alzheimer’s at the time…. When the diagnosis was made he stated that it…put my mind at rest…. Other husbands reported that they had recognised that their wives’ memory was getting worse but
hadn’t fully realised the significance of the changes. Mark, for example, identified that occasionally he …joked [with his wife] … ‘You’d better be careful, you’ll get Alzheimer’s’. Although this statement was made in a light hearted manner, clearly the husband was closer than he realized in his assessment of the situation.

Several husbands related that they had noticed changes in their wives’ behaviour and had been told, after consulting their own doctor, that their wives had developed a dementing illness. Other husbands identified that they knew something was seriously wrong and were suspicious that it was Alzheimer’s disease. By way of illustration, Oswald, reported that

...I had a fair idea of what it was without being told...read articles in the paper, picked up a few pamphlets from the local doctor...In fact, I used to say she had Alzheimer’s disease before she was assessed by the doctor.

Barry related that he had observed that there had been changes in his wife’s behaviour … for many years but that the diagnosis of Alzheimer’s disease wasn’t made until…a little over two years ago…its been a slow process. When asked how he reacted to the diagnosis he stated Look, I knew beforehand. I didn’t need the doctor’s findings to tell me…put my mind at rest.

Several husbands reported that they realised that their wives had dementia but hadn’t accepted the diagnosis possibly because they had an understanding of what
it meant in terms of its poor prognosis and didn’t want to think about this. Eric, for example, stated that when he saw doctor [name] and he said: *Did you know she’s got all the symptoms of Alzheimer’s disease?...I knew it but I didn’t want to believe it.* Clearly, this husband understood that his wife had a dementing illness but refused to accept the finality of such a diagnosis and the prognosis associated with it or was too shocked at that stage to accept it.

To summarise, most husbands recognised that changes had occurred in their wives’ behaviour but didn’t necessarily understand what these meant. Some were suspicious that their wives had developed a dementing illness. For others their meaning became clearer in hindsight but some refused to acknowledge the significance of the problem. When a diagnosis of dementia was eventually made, husbands reacted in various ways. As Frank highlighted when a diagnosis of Alzheimer’s disease was made, *I feel terrible you know, its not nice, is it?*

5.2.4 Its Not Nice

The fourth sub-theme, *Its not nice*, reflected husbands’ reactions to their wives’ diagnosis. For example, husbands reported that when a diagnosis was made they experienced fairly intense emotional responses and commonly used strongly emotive language to highlight their reactions, including *shock, horror, despair, frustration, bit upset, emotionally devastated, disappointed and distressed*. For example, Frank, a 72 year old husband whose wife had dementia for eight years,
stated that he felt…*terrible, its not something nice…It gave me a hell of a shock.*

Similarly, Harry described his reaction as follows …*for me it was just like someone kicked me in the stomach…* .

Several husbands, whilst acknowledging that wives were experiencing something that was deeply disturbing, didn’t always demonstrate an adequate understanding of the significance of the illness. For example, Graham, whose wife had been diagnosed with dementia for six years at the time of interview, reported that it…*could have been worse…as it could have involved physical pain…Its not like she’s riddled with cancer…I can handle something that doesn’t cause pain.*

Another husband highlighted how his wife recognised that she was experiencing significant medical health problems but had no understanding that she had dementia and what this might involve. These responses suggested that particular medical illnesses were viewed as being less tolerable than the current problem. Another possibility is that the wife lacked insight into the significance of the illness or that the illness had not been explained fully to her by a doctor.

Jack, who was also feeling devastated about his wife’s illness still maintained some degree of hope in relation to halting the progress of the illness…*hoping at the time something could be done about the problems .. . All the time you were thinking oh well, it will get better if we keep taking the folic acid.* This statement indicated that Jack did not seem to have a clear understanding of the illness or that he refused to accept that it was progressive and irreversible in its course. Ian’s
response to the diagnosis illustrated that he was denying the seriousness of the diagnosis. As he stated…hasn’t accepted the diagnosis…continued to take her to neurology clinics and give her vitamins…to reverse the problem.

Within the context of changes in wives’ behaviour related to the onset of a significant illness and despite some husbands’ negative reactions to this situation, husbands responded by taking on the care giving role. Reflecting on husbands’ motives for providing care we can conclude that they took on the care giving role for a variety of reasons. Of these, their sense of responsibility, related to their marriage vows, stood out as a strong motivator for family care giving. Arguably, however, the decision to care and continue providing care was not motivated by one single factor but most probably entailed a mixture of reasons.

As Figure 5.2 depicts, the decision to provide care was against a background of changes in wives’ behaviour related to the onset of a significant illness process. Husbands’ interpretations of the meaning of these changes varied and several had reached a correct conclusion of what they represented. Irrespective of the correctness or otherwise of their conclusions, most husbands reacted in almost predictable ways to what had occurred to their wives. Within this context deciding to care may have been an initial decision by husbands but there was a sense in which they choose to provide care on a continuing basis. Moreover, the transition to carer for most husbands occurred subtly and gradually until they were providing a significant amount of care. As the model illustrates, decisions to
provide care were made as they continued to reflect on what had happened to their wives, their interpretations of what these phenomena meant to them, their reactions to the illness and associated changes in behaviour which were dynamic in their development, and the reasons why they decided to become and remain carers. Nevertheless, husbands’ motives for providing care continued to keep them on track as carers even though the role was becoming increasingly difficult.
Figure 5.2

Model of Husbands’ Care giving: The Past

DECIDING TO CARE

Something’s not right
- Couldn’t remember
- Fears & worries
- Doing silly things
- Where are we?

What’s it all mean?
- Something’s wrong
- You’ll get Alzheimer’s
- I knew it was Alzheimer’s
- It’s not dementia

It’s not nice
- Shock, horror, despair
- Could have been worse

Deciding to care
- For better or worse
- Giving back
- Love Game.
When the interviews in this study were carried out it was evident from husbands’ reports that for many of them, care giving had become quite burdensome and some had become depressed. Moreover, wives’ problems had intensified and other problem behaviours had been added to them. In the next section, these phenomena will be examined and a model of husbands’ care giving for the Present described.

5. 3 The Present: Husbands’ Perceptions of Wives’ Present Problems

The second interview question focused on husbands’ descriptions of their care giving experiences at the time of the interview at the time when wives had been diagnosed as having a dementing illness on average nearly five years.

At the time, wives were experiencing various changes in behaviour which the researcher categorized as both cognitive and behavioural and which affected their orientation, activities of daily living, communication and emotions. They were misinterpreting their environment, and losing interest in things that once held their interest. The main theme in the second model was tension created by the impact of care giving demands on husbands’ ability to meet their own basic needs.

Tension between competing demands in model two, created a sense of burden and some husbands had become depressed. Sub-themes identified from the data were Things getting worse, Increased supervision, and Can’t meet own needs.
5. 3. 1 Things Getting Worse

This first sub-theme highlights that some problems identified earlier had become more pronounced and that additional problems had developed, including suspiciousness, wandering, uncooperativeness, repetitious behaviour, aggression, and an inability to complete all parts of a particular task, and potentially dangerous behaviours.

Several husbands reported that their wives were suspicious of others. Suspicions were mainly related to concerns that money had been taken or would be taken by others. One interpretation of this might be that wives had placed money somewhere in the house but had forgotten its location and weren’t able therefore to find it. The focus of suspicions included neighbours. For example, one husband described how that his …*wife hates the sight of neighbour of 40 odd years … gets accused of… pinching money…*; family members, for example, Adam reported in relation to his son-in-law …*he just called in to borrow some money…*[wife’s response was] ‘He’s robbing me’… .

Husbands stated that their wives wandered frequently. Wandering was related to an inability to concentrate for even short periods of time, attempts to continue past behaviours, going somewhere, and wanting to be where the carer was. However, from the information provided at interview there did not always seem to be a purpose to wives’ wandering. Some wives appeared to wander because they were
unable to sit still and focus on any activity for a sustained period of time. Charles, for example, reported that his wife never sits down... *She gets into bed... but she gets up again.* Wandering was also related to attempts by wives to carry out activities that they had been involved in prior to the onset of the illness. Charles asked his wife to join him watching television *She’ll sit down for a minute and then she’s up* [wandering around]... *Puts everything on the table ... that could happen twelve or fifteen times a day... When she gets up... rattles crockery ... [getting] breakfast... .

Wandering represented attempts to go shopping or to see a family member or return to a place where she had previously lived. Charles reported that his wife *Got out on one occasion... found at* [the shops at] *Flemington Markets... how did she get across Joseph Street in the traffic?* Ian described that his wife was *...prone to wander... wandered off down the road to her sister-in-law’s place.* Presumably, she still had some understanding that her sister-in-law lived nearby. Adam illustrated how that his wife’s wandering was related to trying to go to a town where she used to live. Several husbands identified that wives followed them about the house constantly. Wandering here may have been related to wanting to be close to the carer so as to feel more secure. In the words of Charles again, *She’s backwards and forwards, in and out like a yo-yo* [following him around]… . Similarly, Ian expressed being frustrated... *because she follows me round all the time... she wants me... all the time.*
Wives’ repetitive verbal behaviours also made care giving difficult and often resulted in husbands feeling frustrated and angry. Adam, for example, would tell his wife … [name of the person] is not coming over and she will constantly ask when is [name of person] coming over. Eric related that his wife has …got a habit now of asking the same things thousands of times…, for example, ‘What are we going to have for tea’?...and that’ll go on ‘til tea time ... . For some wives’, their behaviour had become quite dangerous as illustrated by their unsafe use of appliances. As reported by Charles, his wife…*burnt front of stereo with iron…held iron against stereo*. Eric stated that his wife…*turned on electric stove and leaves on ... Put [electric] fire on and burnt the door*. These behaviours indicated to the researcher that wives no longer had insight into the consequences of some behaviours, such as being aware of how to use appliances in a correct and safe manner.

Several husbands related that their wives failed to recognise familiar people, places, and things in the environment. Husbands reported, for example, that they were no longer recognised as such by their wives. As Charles stated, *She doesn’t recognise me as her husband ... doesn’t know my name*. Another related how his wife said ‘Well who are you’? and a third reported that he was mistaken for someone else. Failure to recognise their role in the existing relationship left husbands feeling frustrated, upset and even sad. Wives also failed to recognise other family members and even themselves. Others reported that their wives perceived that their fathers and mothers were still present in the home.
Misinterpretation of their environment involved wives getting lost at home, not recognising their own home, becoming disoriented away from home, and generally disoriented. Several husbands identified that their wives got lost in their own home and often didn’t know where they were. As Oswald related, …[she] gets a bit lost in the middle of the night. Another husband reported that his wife Doesn’t know when she comes back home [after they have been out somewhere]. Home and other familiar environments, therefore, were no longer familiar to them. Wives also misinterpreted objects in the environment. As described by one husband, his wife was no longer able to … recognise things in the garden [plants and shrubs] looks as if she’s never seen them before … always had a good knowledge of and a keen gardener … .

Husbands reported that wives were often looking for things such as toilet, light switch, purse and people. As reported by Eric She gets lost, she goes walkabout … She’d go all round the hospital, trying to find the toilet. Charles related that his wife … couldn’t put the light out … looking for the light switch in the most incredible places. Another husband related Every time I go out [wife] spends half an hour looking for a purse… . Daniel and Charles both identified how their wives were looking for their mothers. Looking for objects and people was related to wives’ memory loss, confusion and disorientation and in some instances these changes in behaviour were made worse when away from home or during the night when environmental stimuli were less clear and, therefore, more likely to be misinterpreted.
Wives’ memory loss continued to be an important problem reported by husbands. At this stage it had begun to affect wives’ activities of daily living and information retention. Memory loss included forgetting to eat and that they had taken medications; information they had been given; what they were requested to do, and where things were kept. Charles reported that on occasions his wife…got bread, cereals, fruit [out]. She just peels it, puts it in there [the fridge], and forgets it … doesn’t eat it. Wives had also forgotten information that they had been given. Graham, for example, stated that his wife experienced changes in her short-term memory…you could phone and speak to her…give her a message, and when she’s hung up she’s forgotten what the message was and two minutes later she’s forgotten who’s phoned. Other husbands reported that their wives forgot where things, for example, butter, clothes, were kept in the house.

Several husbands related that their wives’ illness resulted in communication difficulties. They asked repetitious questions, lacked intelligent conversation, were not able to put sentences together, or did not speak very much at all. Others reported that they didn’t understand what wives were saying. To illustrate, one husband stated that his wife was no longer able to…sustain a conversation…try to talk to her…but its practically impossible… start to say something and she doesn’t know what she’s talking about. Charles related that he got frustrated because he couldn’t convey information to his wife as she …doesn’t know what you’re saying.
Husbands reported that their wives were experiencing physical problems affecting bladder and bowel function and mobility. Incontinence was a commonly reported problem. Daniel, for example, was getting up during the night to toilet his wife as she has a tendency to urinate on the floor...she didn’t know where the bathroom was. Some wives were having trouble with their bowel function. Charles related that his wife was...either constipated or she’s loose [has diarrhoea]. Wives were also reported to be experiencing mobility problems. Mark, a 76 year old husband whose wife had been diagnosed with dementia three years earlier, stated that his wife was getting...slower ...and...has trouble sitting ... and walking. Several husbands identified that their wives had become more worried about others and money. Eric reported that She worries a lot...she worries over everything ....for example, George [son] is late...she worries herself sick because he could be mugged ... thinks the worst. Other husbands stated that their wives worried about money.

Husbands expressed that they experienced feelings of guilt. Guilt was related to feeling that they had failed to find a solution to the problems associated with their wives’ illness and that they were not handling the stress associated with care giving especially as the problems were seen as being insoluble. Quentin, for example, expressed feelings of guilt about being stressed and that the stress was not easy to resolve in other ways. In his words
Why should I feel guilty? ... feel as though you’ve failed ... couldn’t get a solution to the problem and as I’ve said to them over there, the stress remains. You cannot get rid of the stress because its different to going to work where you can solve the problem and get rid of the stress ...

This is an interesting statement by Quentin as it highlights that work-related stress can be alleviated but care giving-related stress is constantly present and has no easy solution.

5.3.2 Increased Supervision

The second sub-theme highlights that as wives’ problems intensified husbands’ supervision of their wives had necessarily increased. Increased supervision was related to wives’ wandering behaviour, incontinence, behaviour that placed both husbands and wives in danger, confusion and disorientation, looking for things, inability to dress and undress and go to bed on their own or stay in bed, incontinence, memory loss, and immobility problems. The demands of care giving took an emotional toll and this was described by husbands using the following terms: frustration, worry, anger and getting cranky, getting mad, feeling concerned, disappointed, pressured, anxious and hurt, fearful, irritation, getting nervous, feeling churned up, feeling strain, sad and saddened, feeling inadequate, feeling flat, feeling distressed, feeling on edge and weepy.

Additionally, the nature of their care giving work resulted in husbands taking on increased responsibility for their domestic chores - previously their wives’ roles -
as well as carrying out their other responsibilities. This led to reduced
opportunities to meet their own basic needs, a concept that will be examined next.

5.3.3 Can’t Meet Own Needs

The third sub-theme highlighted husbands’ significant frustrations related to
failure to meet their own needs due to care giving demands and increasing
supervision of their wives. Frustrations were also related to wives’ problem
behaviour, changes in the relationship, extra work, alterations in their own
physical status, reduced time to undertake hobbies, activities, and future plans.
Each of these will be described next.

Frustration was commonly associated with wives’ memory loss. As one husband
stated At times ... puts purse under the mattress and forgets where she puts it. For
Barry it was related to his wife’s nuisance behaviour. As he described I have to
sew on all buttons that she keeps pulling off ... . Daniel, who had been providing
care for one year, was frustrated because his wife hid the household money.
Charles related that he got very angry with his wife when she deliberately did
something that he had asked her not to do ... the more you ask her not to touch
something or ‘Don’t do that’ ... she’ll do it. That’s when you get uptight. These
problems resulted in the need for increasing surveillance of wives’ behaviour and
decreased the time husbands could give to meeting their own needs.
Some husbands reported that wives failed to pass on phone messages or remember who phoned. This effected, in some cases, husbands’ opportunities to respond to friends’ calls and keep in touch socially. Wives’ wandering meant that husbands had to be constantly alert particularly where wandering placed them in danger. As reported earlier in the chapter, some wives followed their husbands around all the time. Others got up during the night and caused much concern and worry about what they might be doing. Husbands were often reluctant to leave wives on their own as they couldn’t be trusted not to do something dangerous or wander off. As noted earlier, Eric’s sleep was disturbed on a regular basis as his wife often got up during the night and put the electric fire on and burnt the door. The net effect of these concerns for many husbands was lack of sleep and a continual sense of tiredness. For others care giving interfered with work responsibilities, for those few husbands who still worked part-time, as they worried about what wives might be doing.

Husbands’ need to communicate in a meaningful way with their wives was often affected. Oswald reported that...[his wife] mumbles to herself and talking to herself... it...makes me mad ...because he couldn’t understand what she was saying. Wives’ behaviour interfered with husbands’ attempts to relax and watch TV. Husbands’ needs for companionship, sexual intimacy and recognition were also affected by their wives’ illness and this was investigated by the third interview question, “How do you feel about your relationship now?” Relationship problems and issues will be described next.
Relational consequences associated with changes in wives’ behaviour included a lack of communication and companionship, changes in physical intimacy, changes in husband-wife roles, failure to recognize carers as their husbands, and reduced companionship. As reported earlier (Section 5.3.1) several husbands related that their wives’ illness resulted in communication difficulties. For example, some wives were unable to sustain a conversation for very long and for others no conversation was possible thus decreasing normal social discourse between wives and husbands. Several husbands reported that no further sexual relations were possible. As stated by Jack… *as you may or may not know, our sex life has not been going* [it was non-existent]… . Husbands generally were distressed and sad that wives no longer recognised them as their spouses and mates. This resulted in feelings of hurt, frustration and sadness.

Care giving, for many, involved taking over their wives’ traditional role in the home. Neville, for example, reported that he was experiencing… *pressure and… strain and didn’t know how long it [care-giving] can continue… as he was… working during the day and coming home to get the evening meal, do washing, ironing and cleaning*. Also he had taken over… *all the banking, shopping, her car [fixing and maintaining it], letters… doing her Christmas cards and mail*.

Extensive care giving prevented husbands from being socially active. Husbands were not able to visit friends, stay with family members or go to the shops and
dinner parties at friends’ places. Choice restriction was illustrated by Charles who stated *It’s a terrible thing to wake up in the morning and say I can’t do this, I can’t do that. I’m more or less a prisoner and this is what effects you*. Similarly, Barry reported *You are stuck here, reading, watch the idiot box or listen to music. Friends do call now and then, but I can’t go [out]*… Care giving prevented husbands from going on holidays. For example, Oswald had tried to stay with his daughter for a few days and in his words *We arrived there in the afternoon and about 11 o’clock at night my wife said ‘Come on Dad, its about time we went home’.*

Carers’ need for sleep was often interrupted and carers were often feeling tired and exhausted. Tiredness, for example, was caused by getting up early and having to be constantly alert. Quentin reported being very tired because he had to get up early each morning to take his wife to the toilet so that she wasn’t incontinent. Charles experienced tiredness due to having to be alert all the time. As he stated

*…can’t go to bed until she does. Can’t sleep thinking about [what she is doing] … always listening for wife… got to have your eyes open all the time…she might be there [bed] for five minutes and then she’s up again.*

Several husbands identified that because of care giving they had to forego involvement in previous hobbies and activities. Jack stated *I don’t have enough time to do some of my hobbies. I’ve got sheets in there of all last year’s stamps. I haven’t had a chance of getting round to putting them in [an album].* In
Oswald’s own words … *can’t play bowls anymore.*

For several husbands taking on the care giving role meant that they had to shelve their plans for retirement which included doing part-time work and generally enjoying retirement years. As Larry stated *Thought I could continue to supervise trainee doctors at home part-time but it didn’t go ahead… I feel my main role is as a caregiver. Should have been enjoying life…*. Eric was unable to visit relatives and friends in his country of origin. As he stated *I did want to go home [England] this year and I mentioned to doctor [name] …they [doctor] preferred her to be [here] at home…I feel disappointed…So, it just upsets me. I wish I was home…*.

The extra work associated with care giving and undertaking their usual responsibilities at the same time involved having to do everything for their wives, interrupted sleep, constant supervision and having to be constantly alert.

5.4 Contradictions in Husbands’ Evaluations of Care giving

Several husbands reported that care giving wasn’t such a problem for them but when this assertion was investigated further it was found that their responsibilities were making them feel angry and cranky. Information from the interview data illustrated this finding. Oswald stated that he did not experience any worries in relation to care giving…*I didn’t think it [the illness] was going to get this*
worse...no, its not worrying me to do any of this. Moreover, he identified that even though his wife experienced problem behaviours, for example, ... she gets cranky and screams at me ..., he was still able to manage her ...It doesn’t worry me because I’m retired, I’d never do it if I had to go to work, of course. However, on closer examination of the data it became clear to the researcher that this was not the whole story. Another husband, Nigel, reported that ... we can cope quite well ... its got its problems ... but its not... insurmountable ... he related later in the interview that he didn’t know ... how long it can continue ... with the pressure and the strain ... . Finally, Graham, said that there hadn’t been

...problems looking after wife ... I can honestly say its not given me any [problems]...Part of me would have to be a saint or a very special person ... Accept lack of intelligent conversation ... lot of her conversation with me is just agreeing with me ...I’m not under any stress.

However, later in the interview he acknowledged that care giving ...had led to...a dramatic role change [for him].

These findings highlight that some husbands thought that that they were managing but really weren’t, or that they believed that they had to project an image to others that they were managing as it was expected of them that they should, as men, be doing so.

In summary, the data presented in this section suggest that in relation to the work of care giving, many husbands were feeling burdened and some were depressed.
Husbands’ sense of distress was related to a multitude of factors which impinged on their daily activities, including their ability to take ‘time-out’ and experience a sense of personal space. It was also related to a narrowing of their current and future horizons. Inconsistencies between stated major problems in care giving and reluctance to concede the extent to which they were affected by these may, in fact, have reflected both a significant level of ambivalence and raises the possibility that their apparent stoicism may have been gender-related.

Having addressed interview questions 1. “How did you come to be looking after your wife?”, 2. “Can you tell me what it has been like to look after your wife?”, and 3. “How do you feel about your relationship now?”, the writer will move on to the fourth interview question which requested that husbands reflect on their care giving practices or activities.

5.5 Care giving Practices

The fourth interview question asked husbands to describe their care giving practices. Most husbands, carrying out a range of care giving activities, initially relied solely on their own efforts but many had become physically exhausted because of the constant care demands. Despite this, it was evident that they had become involved in a range of diverse care giving tasks and activities, committed to direct care, and assumed overall primary responsibility for their wives’ care.
Also of interest was the amount of care giving effort that husbands expended and financial costs associated with providing care. Husbands indicated that they provided care at least half of the day and many were providing care for the whole day. Moreover, they reported spending on average $27.00 on care giving activities and this created additional burdens for those husbands, approximately half the participants, whose main income at the time was a pension.

For a majority of husbands, secondary support was provided by family members who lived elsewhere. Many family members were not available to provide direct support because of geographical distance but visited from time to time or kept in touch by phone. The extent to which this provided emotional support for carers was not investigated in this study. However, as husbands became aware of outside services and agencies, they tended to sample these, and were able to describe positive experiences as well as their individual evaluations of those they perceived as less useful.

The following section begins with husbands’ personal and instrumental care of their wives and is followed by their outreach to support services.

5.5.1 Personal and Instrumental Care giving

A major part of the day involved providing personal care of wives and attending to instrumental activities of daily living. Personal care included assistance with
toileting needs and continence problems, washing and showering, brushing teeth, and dressing, as well as cleaning up after these activities. Several husbands reported that they were not comfortable with providing personal (‘intimate’) care, nor more traditional household activities (washing etc) that wives would normally have assumed within this age group.

Several husbands had sought support and advice from an occupational therapist in relation to activities of daily living problems. Modifications, for example, had been made around the house to facilitate day to day activities where there were difficulties, for example, where a wife couldn’t turn off the shower tap; buying a commode for the bedroom; putting signs on doors and handrails in the bathroom and toilet area to prevent falls. Husbands also received advice from hospital staff about purchasing incontinence pads for their wives.

Care giving was a difficult activity and within the care giving context many husbands had developed self-management and other strategies to manage wives’ problem behaviours. Both will be described in the next sections.

5.6 Husbands’ Self Management Strategies and Strategies Utilised to Manage Wives’ Problems

Husbands utilized various strategies to enable them to cope. Self-management strategies included thinking about the good times, not looking too far ahead,
focusing only on what could realistically be done, taking time out, being
organized, seeking support through relaxation therapy, religious beliefs and
practices and finding out more information about dementia and care giving-related
issues by attending lectures and talks.

Husbands utilised a range of strategies to manage wives’ problem behaviours.
These included doing things together, doing things wives liked doing, letting
wives have their own way, keeping them occupied, altering the physical
environment, use of vitamins and medications and information seeking.
Husbands related that doing things together was a useful management strategy and
included keeping wives company, occupied, providing ongoing stimulation,
encouraging communication, exercise and the use of old skills. Using these
strategies probably also enabled husbands to provide ongoing supervision and
contributed to their overall management of wives’ behaviour.

Doing things together presumably provided a sense of security for wives. Doing
things that wives liked doing conceivably reinforced a sense of familiarity and
kept them motivated to the extent to which this was possible. Letting wives have
their own way arguably reduced potential conflict. Keeping them occupied
provided some structure to their day and may have reduced problem behaviours
and made them feel more secure. Seeking information about the illness allowed
husbands to make more sense of their wives’ problem behaviours and enabled
them to manage them more appropriately. However, use of vitamins and some
medications was not a management strategy as such but suggested that some husbands did not fully understand the prognosis associated with such an illness or were unwilling to accept it. Alternatively, it could be that their use made husbands feel better and that they were contributing in some tangible way.

In summary, husbands utilized a range of strategies to handle wives’ problem behaviours associated with their illness. This is understandable as no one strategy would of itself be adequate for such a situation.

Husbands also used various supports to assist them to manage wives’ problem behaviours better.

These will be explored next.

5. 7 Supports

The fifth interview question asked husbands to describe supports that they were receiving at the time of interview. In the present study, support for husbands was provided mostly by family, friends and neighbours and to a lesser extent by the general public, although supports were not always perceived by husbands to be helpful. All other assistance was clearly always secondary compared to that provided by husbands.
Husbands related that family members provided varying levels of support. Adult daughters were mentioned most often by husbands as providing more support than any other relative or person. Other family members providing support included sons, a granddaughter, sister, sister-in-law. Supports offered by children, especially adult daughters, included a range of activities including visiting, taking their mother to other family members’ homes, doing the washing, having their father and mother over for meals, assisting in emergency situations, keeping in touch by phone, taking mother shopping, getting information, for example, books, pamphlets, about dementia, providing emotional support for carer, staying over, supporting carers’ decisions relating to mothers’ care, being understanding, making meals, providing opportunities for parents to stay over, offering to help, providing respite for carer, visiting mother at day care, keeping in touch by phone and taking mother shopping.

Where husbands identified a lack of family support they attributed this to family members’ work responsibilities, being taken up with their own problems and geographical distance. However, not all family members were described as being supportive and one husband reported having to ask for help. As he related he was frequently ... abused by step daughters ... they don’t understand. Another husband stated that his care giving activities were interpreted as... usurping his wife’s role.

Husbands received support from friends, neighbours and the public. For some
husbands neighbours were supportive but for others they weren’t. Several husbands had friends who visited and brought meals. Although most husbands reported that neighbours were helpful their support was not always appreciated by wives. For example, according to one husband, *Neighbours ... they’re very good, and they come over and have a cup of tea, but she doesn’t want to chat with [any of] them.* For others, friends rang them on a regular basis presumably to provide emotional support. Husbands also received support from various external services.

5. 7. 1 Supports: Formal Supports for Husbands

Husbands reported utilising a range of external support services. These included respite care, day care, home care, Alzheimer’s Disease and Related Disorders Society (ADARDS) support groups, hospital and nursing services, and meals on wheels.

Day care was the formal support service most utilised by husbands with over half reporting that they utilised it between one and five times weekly. Day care usually commenced at 9:30 am and wives returned home around 3pm. Cost was approximately $2.50 per visit. Usually, husbands utilised the day care centre nearest to them. Several found it expensive to transport wives to and from day care. For Frank, a 72 year old husband, who had been providing care for eight years, day care…*was a god-send ... [staff] …look after them. Its a home away*
from home ... they are [treated as] persons there. He identified several advantages associated with day care, specifically, the small numbers that attended, therefore … get to know each other’s needs…[the staff] understand…greater understanding of people with dementia…and staff communicate what has been happening with wife during the day…. 

Frank, for example, described how that day care afforded him the chance to go shopping. Adam, a 67 year old carer, who had been providing care for two years, stated that such care was beneficial both for his wife and himself…she’d been in what they call respite…. Another indicated that it provided a welcome relief from care giving stating I’m glad that I have been able to have a respite.

However, day care was not always perceived as being helpful as Oswald, a 79 year old carer of 12 months, reported...day care was too depressing [for wife] …more worrying for [him]. Possibly, it provided a continuing reminder that his wife would deteriorate as he observed others with the disease, or perhaps it represented a fear that she might not be receiving proper care. Although respite care provided husbands with a period of temporary relief from care giving, they were not always pleased with the care that wives received in respite care. In Adam’s words …the time before when I brought her home, I found out that she had no underwear on, it made me think where’s all the caring?

Home care services were an inexpensive means of support and were used by
several husbands. For David, a 70 year old husband who had been providing care for one year, it was the only service he was utilising at the time and he found it cheap to use at $6.00 weekly. Another husband stated that he received home care services on a fortnightly basis. Services provided included vacuuming and ... *person from home care cleans up generally*. One husband, however, related that he had experienced some problems with home care services as ... *man [who comes] broke his leg 3 weeks ago and they promised to send another handyman but hadn’t heard from them since.*

Surprisingly, only two husbands reported receiving meals on wheels. It seemed that most husbands, therefore, were providing meals for their wives and themselves. For some, other family members gave invitations to meals or provided the odd meal. In addition, several husbands received meals from members of the church they attended when they could.

More than half of the husbands in the study identified that they attended ADARDS support groups. These support groups met four basic needs of carers: educational, mutual support, opportunity to discuss caregiving experiences, and opportunities to ventilate feelings. Frank, a 72 year old carer of eight years, who had been attending a support group for four years, reported that he had been … *taught how to relax, and how to cope...*. He had also found lectures from a doctor who spoke at the group he attended to be … *very useful ... Helps me to care better for her, [teaches me] how to relax, not to lose my block...*. Another
husband who had attended a stress management course at a hospital-based
ADARDS support group stated *I’m not under any stress, but I felt that if I do the
course, I’ll be better equipped to deal with stress if it does occur.* Support group
discussions had proved helpful to several husbands. One reported that he attended
a support group two or three times... *Just pop in and say ‘Hello’... people
discussing how to help with stress and things like that.* Another husband related
that attending groups assisted him to *Get ideas about how to handle problem
behaviour...problems sleeping.*

Advantages associated with the support group were seeing others and hearing
others’ experiences, small group discussions, talking about experiences, learning
from others, testing what husbands were doing against their experiences and
others can learn from you. However, husbands’ experiences of ADARDS groups
were not always positive and beneficial. Ian, a carer for eight years, for example,
reported that... *nothing new was learned...from attendance.* He also related how
that he got upset from listening to the stories of other carers. Presumably, these
discussions highlighted the progressive nature of the illness that his wife had.
Similarly, Oswald, a carer of six months, related that groups were a... *waste of
time...as he listened to the...repetitious stories of others....* Arguably, his wife’s
illness was in its early stage and he may not at the time have been able to judge
how much he could benefit from the group as his wife’s illness progressed.

Local hospital support services utilised included assessment of wives on an
outpatient basis, advice and assistance with home improvements, help from Occupational Therapists (OTs), lectures and talks about dementia and dementia management, relaxation classes, organisation of respite care, visits to carer and wife, provision of advice and encouragement to use institutional care, and arranging for respite care. Local hospital resources were reported as being excellent by two husbands and hospital staff was described as kind by Oswald.

As the researcher is a nurse by profession and lectures to nurses in university courses he was interested to identify and examine the ways in which nurses met the needs of husbands who were providing care.

Husbands reported that nurses visited, rang, provided emotional support, stayed with wives (so that the carer could take time out or do other things), arranged respite and Carers’ Pension, provided advice about physical problems, and engaged in ongoing assessment and follow-up. Visits by nurses varied from husband to husband and ranged from one to three times a week although several husbands stated that they presently received no nursing support. One husband related that he did not need nursing support at present. Another stated that nurses carried out a range of activities, including keeping in contact, providing support and showing concern, taking his wife out and providing practical assistance when needed by them. In his words, Community nurses ring up ... ’I come up for an hour’?...Which they do. His assessment was that he was pleased with the nurse’s support as she was genuine in her concern ... All I have to do is ring and we
can get someone to put her in the bath ... Takes her out...[she] won’t go with anyone else ... Checks on whether things are okay.

Nurses were involved in ongoing follow-up and assessment. As identified by one husband ... he [the nurse] wants to visit to see how I was going. When the nurse visited the carer he asked how...they bathed her over there [in hospital] and how to overcome that [the problems] ... [he was] experiencing when trying to bath ... wife. Another reported receiving ongoing visits from a nurse from the local Hospital once or twice weekly. When asked by the researcher what the husband perceived was the purpose of the visit he stated ... mostly seeing that she’s alright ... asks whether she’s showering ... how she is sleeping? Ian, a 70 year old carer perceived the nurse’s role as providing backup for him as the primary carer. The nurse had informed Ian of the availability of the Domiciliary Allowance Benefit and had assisted him to obtain it. Still another husband received advice about his wife’s physical problems, specifically she had a rash under her breasts and ... the nurse said to use Curash. I had been ... using Johnson’s Baby Powder.

Husbands’ experiences with nursing support were not always helpful and positive. For example, Charles, a 67 year old carer for two and a half years, reported that a nurse had been coming to bath his wife but that seemed to make her more irritated and upset, and that...she would sort of hang and cling to him [husband] right through the day ... wouldn’t accept it ... it makes her more agitated. To discuss this situation, he... tried to make contact with the nurse at [name of hospital] ...
said [name of nurse] would be out [to visit] but hasn’t yet.

In summary, husbands utilized a range of services, perceived by husbands as helpful in the main. The most frequently used was day care. Several husbands also used respite care and this allowed them to do other things. Husbands were taking care of their homes and surroundings and preparing meals. More than half the group attended ADARDS support groups. For many, these provided emotional and educational support, however, a small number reported that they learned no new information or that they became upset as they listened to others’ stories. Local hospitals provided a wide range of services including assessment, advice, information, therapies and organized appropriate support services, for example, occupational and physiotherapy. Nursing services included provision of emotional support, in-house respite care, advice and ongoing assessment through follow-up. However, while several husbands currently had no contact at all with nursing services they recognized that they would need this type of support in the future when wives’ problems worsened.

As a final point, and in response to the sixth interview question, husbands highlighted the need for significantly more assistance from family members, for example, more understanding and practical support, community nurses and from respite care agencies, to allow them to obtain periodic relief from the intensive demands of providing home-based care for their wives. Additionally, some husbands wanted ongoing opportunities to share problems with others in a similar
situation.

5. 8 Model of Husbands’ Care giving: The Present

At the time of interview, husbands were experiencing an increasing sense of burden and some were feeling depressed. Their distress stemmed from illness-related changes in their wives’ behaviour, the resulting changes in the spousal relationship from one of partnership to increasing dependency. The nature of the care giving work exacerbated this by adding additional responsibilities, the overall effect being to reduce husbands’ amount of personal freedom and choice. These factors impacted to such an extent on husbands that they were unable to meet their own needs. Specifically, they were unable to go out or visit friends or participate in recreational activities; meet their sexual needs; they experienced interrupted sleep; were unable to spend time alone or go on holidays; nor invite people home for meals; or make plans for the future. Failure to meet basic needs resulted in husbands feeling tired, frustrated, lonely, sexually frustrated, pressured, strained, guilty, isolated, exhausted, disappointed and depressed.

The derived model related to the Present (Figure 5.3 over page) highlights that husbands’ sense of burden resulted from a state of tension associated with a variety of stressors and the impact of demands of care giving and responsibilities on their ability to meet their own needs. Husbands who felt burdened could easily have become depressed and depression could have led to a greater sense of burden
as care giving responsibilities would have seemed more onerous. For many
husbands, tension was partially reduced through various strategies and activities
including engaging in outside support, family and other support, and utilising
various management strategies, and strategies that made wives’ problems more
manageable. That is not to say that these strategies always worked or that they
always enabled them to meet their needs better. The model proposes that where
tension reduction strategies failed that this may also have resulted in an increased
sense of burden.

**Figure 5.3**

Husbands’ Model of Care giving: The Present

- A. Stressors
  - behaviour
  - Choice restrictions
  - Feeling of failure
  - Sense of isolation
  - More responsibilities

- B. Increasing supervision

- C. Couldn’t meet own needs

- Tension reduction related to
  - Other’s support
  - Outside agencies
  - Support groups
  - Self management
  - Wife management

A+B+C= TENSION
Although there wasn’t a lot of data derived from the interviews about husbands’ thoughts about the future and this was not a specific interview question, it is clear that some husbands had thought about this and what the future might hold for them and their wives. From the interview data, therefore, the researcher was able to gain some insights into husbands’ thoughts about and perceptions of their future experiences as care givers.

5. 9 The Future: Husbands’ Predictions of Future Events

Husbands’ concerns about what the future might hold were based on listening to other care givers’ experiences about the progressive nature of the illness at support group meetings and from an increasing understanding of the significance of the prognosis that normally attends a diagnosis of dementia. The main theme for husbands’ model of care giving for the future was Fear of the Future and sub-themes were Discouraged, Further deterioration and Doubts about continuing in the role.

Fear of the future for some husbands led to feelings of discouragement and this was related to husbands’ perceptions about their wives’ continuing deterioration. Mark, for example, reported being worried about the future. As he stated
I see some of the people out at [name of hospital] and it certainly doesn’t encourage you very much, and you read about…well, she’s not deteriorating rapidly, but it’s a tremendous change…She is now an elderly old lady…which seems to have happened fairly rapidly…I’m fearful of the prognosis that she will, you know, not recognise us, and she will become…like a vegetable

A sense of discouragement was also related to the effects of their wives’ disability on their future life circumstances. Eric, for example, regretted not being able to visit his country of birth and he felt that he had missed out on the benefit of his family’s support and comfort and security for his wife in her progressive decline. For Ian, attending ADARDS support group reminded him of his wife’s further deterioration. Nigel reported that he didn’t know how long he could endure the pressure and strain of care giving and could not envisage anything positive in the future. The second sub-theme highlighted that wives would continue to deteriorate and that changes in wives’ behaviour would result in failure to recognise those near to them including their primary care giver and that they would be left with very few functional abilities.

Doubts about continuing in the role, the third sub-theme, resulted in a sense of pressure and strain as they contemplated their inability to continue in their role as carer and entertained the idea of placing their wives in institutional care.

The future model of husbands’ care giving (Figure 5.3), indicates they believed that things would only get worse as the disease progressed. As they thought on
this and the impact that this would have on them personally, husbands acknowledged feeling *saddened, discouraged, fearful, upset, worried, under pressure*, and *a growing sense of doubt about their ability to keep going*. 
5. 10 Conclusions

Husbands described the changes that took place in their wives’ behaviour with the onset and progress of dementia. For all wives, changes had been present prior to a diagnosis being made and husbands had assumed varying degrees of responsibility for managing changes to their wives’ behaviour. Wives’ memory loss, disorientation to time, place and person, diminished ability to self-care, wandering and greatly increased dependency, were highlighted. Husbands’ interpretations of the significance of these changes varied, with some husbands recognising what they represented while others were unsure. Husbands’ reacted
to a diagnosis of dementia with intense emotional responses but a few husbands tried to ‘down play’ the significance of the illness. For others, it confirmed their suspicions. Some wives retained varying degrees of insight into the fact that they had developed a significant illness although they did not necessarily appreciate its poor prognosis.

Husbands continued in their usual roles and activities but to these had been added those that had previously been carried out by their wives, such as shopping, cooking and housekeeping. Some husbands reported engaging in a variety of care giving activities including intimate and personal care although they were not necessarily happy with having to attend to this.

Motivation for providing care included a genuine reluctance to institutionalise wives, love for wives, an appreciation that wives had a greater sense of security being cared for in a familiar environment by a familiar primary caregiver, but most importantly their marriage vows.

At the time of interview, wives’ behaviour had become more problematic and the demands of care giving resulted in husbands being unable to meet their own needs. Consequently, many of them were experiencing an increasing sense of burden and some had become depressed. As they thought about the future, husbands felt pessimistic about their ability to continue as carer as it was perceived that wives would continue to deteriorate and they wouldn’t be able to
To verify findings in stage one of the study, the material in this chapter was sent out to one of the carers in the study (Larry) and four other older husbands who were providing care, but not in the study cohort, whose names were provided to the researcher by Alzheimer’s Association.

5.11 Verification of Findings

As described in Chapter Four, Burns & Grove (2005) have proposed that there are a number of strategies to enhance validity of qualitative research. One of these is obtaining feedback from informants. They suggest that feedback provides verification of the information obtained in research studies such as this. Polit & Hungler (2001) refer to informants as ‘external judges’ (p.437) and their role is to assess whether the findings of a study are trustworthy and valid.

To enhance the validity of the study, five older husband-carers were identified by the researcher to reflect on the study findings and the models that were developed. Only one husband (Larry) had been interviewed in stage one of the study as other interviewees’ circumstances had changed and Larry was a particularly articulate participant. In addition, and following Polit & Hungler’s (2004) proposal that other external judges (other older husbands who were also providing care for wives with dementia at home), four husbands were identified from Alzheimer’s
Association support groups as these were readily accessible and willing to review the study findings. The four husband-carers were provided with names by the researcher that bore no similarity to their real ones. Chapter Five was then sent out to each of these and they either wrote their responses at the end of the chapter provided or within the chapter itself although they had been encouraged to write their findings as a separate paper. Notes within or at the end of the chapter provided their reflective comments based on their own and other older husbands’ experiences who were providing care for wives at home with dementia and with whom they had contact. Responses to the chapter findings indicated that there was overall general agreement with the study findings and the models of husbands’ care giving that were developed. In addition, husbands provided examples of their own experiences. Several had shown their copies to other male carers with whom they were in contact, for example, by attending support groups, and all were in general agreement about the writer’s findings.

Larry agreed with the findings that communication problems were a significant issue for carers. Moreover, he highlighted that carers took on more and more responsibility as wives’ condition deteriorated further. Additionally, he agreed that husbands generally were saddened at the changes they observed in their wives’ condition. Greg, a non-participant in the study, felt that model one and description of the data supporting it, was reflective of attitudes of most husbands I know whose wives have dementia. He reported that things were getting worse and that this situation would only deteriorate further. In relation to model two, he
stated that he spoke to friends and mates in the same situation and that both he
stated that he believed that this represents events as explained by them. In relation
to model two he related that it says it all. Greg agreed that older husband carers
are their own worse enemies as they keep most things to ourselves…not even
sharing with families.

Benny reported having difficulties cooking meals and that there were occasions
where he became impatient and anxious about his wife’s behaviour, for example,
when she didn’t come home from the shops. He related that he was still able to
engage in some of his pursuits, for example, gardening, seeing friends, inviting
others over. He has also found members of the support group to be very useful
and that he found day care…most useful, and in-house respite was also described
as being very useful. Warwick also related that support groups were

        a great advantage for carers…brings together people
        of a similar age with similar lifestyle and problems…
        provides an environment that easily facilitates conversation
        on a wide range of issues…easier to talk.

He emphasised the importance of keeping his wife company. A final note, made
by Benny, indicated that the information in the chapter seems to represent
husbands’ experiences accurately. I speak for myself and other husbands at
support groups. Finally, Warwick had viewed his upcoming retirement as
comprising a relaxed and easy lifestyle…[but]…a real shadow falls across your
life…simply one finds as if part of their life and existence has been stolen. He
described how that he learned to accept the situation but *as time goes by they [husbands] feel their life has been snuffed out.* In relation to the four models presented in Chapter Five he stated that he agreed *in an overall sense with most of the comments expressed and views stated by the various male carers.*

From these comments the writer felt confident that there was general agreement that the researchers’ interpretations of the interview data and the models derived from that data were an accurate reflection of husbands’ experiences of care giving although husbands didn’t comment about all aspects of the findings.

Findings from stage one of the study facilitated the development of stage two. Findings indicated that husbands commonly experienced a sense of psychological distress associated with caregiving. In stage two, the researcher aimed to confirm the notion that husbands experienced both a sense of burden and some had become depressed in relation to their care giving. In addition, it was intended to examine the unique contribution of specific variables from stage one to identified measures of husbands’ burden and depression which were described in Chapter Four.

In Chapter Four, the writer identified that there were several other sources that were employed in the development of a questionnaire for stage two of the study. These included relevant research literature, reflections on the writer’s previous caregiver studies, discussion with staff of aged care and aged care psychiatry.
services, as well as the researcher’s supervisor.

Seventy-one husbands who were caring for wives at home with dementia completed the questionnaire and responses to questionnaire items were analysed descriptively and findings presented in Chapter Six along with questionnaire variables regressed on husbands’ burden and depression scores. This regression analysis is reported in Chapter Seven.
This chapter provides a descriptive analysis of the cluster variables. In summary, husbands were providing care over many hours daily. Against this background efficiency & organisation was highlighted. Changes in feelings towards wives were highlighted. Many husbands felt unsupported in their care giving effort.

Introduction

In this study of home-based care by husbands for their wives with dementia, husbands were providing care over many hours daily. Against this background, husbands focused on being task-efficient and organised and their relationships with their wives became imbued with a sense of burden. Additionally, many husbands felt unsupported in their care giving efforts and others were depressed. This short chapter provides a descriptive analysis of the statistically significant cluster variables associated with husbands’ burden and depression.

In order to provide a more complete picture of the data, the descriptive analysis of the data is organised and presented under each of the variable clusters identified in Chapter Seven. The number of variables in each cluster ranged from four to nine. These were described in Chapter Four.
In this descriptive data analysis, values with decimal points between 0.1 to 0.5 were rounded down (for example, 24.3% becomes 24%) and those values with decimal points 0.6 to 0.9 are rounded up to the next whole number.

6. 1 Cluster One Variables: Husbands’ and Wives’ Demographic Variables

Husbands’ ages ranged from 56 to 86 years (mean 73.93; SD=7.22). Twenty-five (35%) husbands were born overseas. Most husbands had completed a high school certificate, with twenty-three husbands (32%) reporting that they had completed a Technical, College or University course. More than half (59%) of the husbands in the study identified that their main source of income was a pension, for example, Aged or Veteran’s Affairs Pension. A high proportion of husbands (77%) related that that they had a religious affiliation. Forty-three husbands (61%) lived in the metropolitan area of Sydney and the remaining 28 (39%) lived in rural New South Wales.

Wives’ ages ranged from 59 to 88 years (mean of 73.66; SD=6.65). Many (72%) were born in Australia. Husbands reported that a small number of wives (17%) had completed post-school education and most (76%) identified that their wives were in receipt of a pension as their main source of income.
6.2 Cluster Two Variables: Characteristics of Caregiver Effort

From a descriptive analysis of the data, forty-six husbands (65%) reported providing direct care for between 10 and 24 hours daily and twenty-four (34%) for 24 hours daily. These figures indicate a high level of supervision was being provided by all husbands. Husbands’ estimate of indirect care giving time indicated a mean of 5.93 hours (SD=6.25). Indirect care giving activities included shopping, paying bills and doing banking on behalf of wives.

6.3 Cluster Three: Husbands’ Perceptions of their Role

Fifty-five percent of husbands reported that care giving was ‘Mostly’ or ‘Totally’ like a job. Of these, 21% related that there were aspects of the care giving role that were like the job they used to do. To illustrate, husbands emphasised service to the public; having to make decisions on behalf of others; supervision and planning ahead and exercise of careful finance management. One husband reported that he had been a nurse for over 40 years and had been used to providing care for others.

Twenty husbands (28%) reported that experiences in their previous job helped them to carry out their present care giving role. A high proportion of husbands (84%) ‘Mostly’ or ‘Totally’ agreed that efficiency and organisation on a day-to-day basis in relation to care giving was important. More than three quarters of the
group (77%) reported ‘Mostly’ or ‘Totally’ that the present role of carer was an important one.

6.4 Cluster Four: Effects of Care giving on Husband and Wives’ Relationship

The questionnaire contained several questions designed to explore emotional and relational aspects of husbands’ care giving. Specifically, Questions 6, 18 and 37 focused on husbands’ perceptions of the extent to which care giving responsibilities and changes in wives’ condition impacted on their relationship.

In Question 6 husbands were asked to indicate how close their relationship was with their wives. A high proportion of husbands (91%) reported that the relationship with their wives was still ‘Mostly’ or ‘Totally’ close still.

Question 18 requested husbands to identify if their feelings had changed towards their wives since the onset of the problems. Many of the husbands in the study (84%) identified that there had been little or no change. Where changes in feelings were reported these were related to the following: wife had become a child and in need of loving care; hard to talk to as she gets upset; feel sorry for her; worry; concern; she hates me; no intelligent conservation possible; loss of love; get cranky at times; getting blamed; a different person; wife is moody. These responses indicate that changes in feelings were related to wives’ behaviour and the ways in which husbands were being affected by these.
A third question (Q37) asked to what extent, if any, care giving had affected husbands’ relationship with their spouses. Fifty-six husbands (79%) stated that there had been little or no effect on it. Where changes in the relationship had occurred these were reported to be related to Effects of care giving on husbands’ feelings, sense of confidence, and ability to manage; Changes in wives’ ability to manage; Consequences of changes in wives’ behaviour on the relationship; and Changes in husbands’ and wives’ roles.

Husbands reported that they had become stressed, frustrated, suffered mood swings, become tired, easily upset, irritated, impatient, and confused. One husband related that he lacked interest in anything and had lost confidence in his ability to manage. Sixteen (22%) husbands identified that they had experienced changes in their physical health status related to their role as carer. Husbands also reported that wives required increasing amounts of supervision, changes in wives’ behaviour had impacted on their relationship and caused changes to their more traditional family roles.

Husbands reported that their wives were now worse and that this meant that they had to look after them more and more on a day to day basis. One husband, for example, related that he had to do everything for her. Another identified that his wife was dependent and demanding and still another that there was no response and that his wife had become more childlike.
Several husbands identified that significant changes had resulted in respect to their relationship with their wives. One, for example, related that they were no longer man and wife. Loss of companionship was also highlighted by others. Husbands also reported that there was no affection left and a small number of husbands (3%) related that no sexual relationships were now possible. Other changes included loss of companionship, loss of joint decision making, little in common left, no communication possible, no sharing of life’s ups and downs. However, several husbands identified important positive effects, for example, that care giving had brought them and their wives closer together. In the words of another husband I love her more everyday and another that he felt more protective of his wife.

Several husbands reported that the development of dementia had resulted in significant role changes. In particular, one husband highlighted that his role had now changed to that of parent.

6.5 Cluster Five: Effects of Care giving on Husbands

Thirty husbands (42%) reported engaging in previous care giving experiences. Although respondents were not asked to provide examples of such experiences, the example given by the researcher to guide husbands’ responses was, for example, regular responsibility for children. Less than one-fifth of the group (18%) reported that previous experiences were ‘Mostly’ or ‘Totally’ helpful to their present role as carer.
6. 6 Cluster Six: Supports: Relatives, Friends; Religious Beliefs and Practices

The assumption that relatives, friends and religious beliefs and practices can be comforting in times of burden and depression is frequently validated on a personal level, but may not necessarily be factual when variables from survey data for a group are analysed. Husbands reported varying degrees of support from these sources.

Nineteen husbands (27%) related that there were no relatives or friends that provided support for them in relation to their care giving responsibilities. Forty-five (63%) stated that they had between one and three relatives or friends and seven (10%) between four and six who provided some level of support. Notably, nearly two thirds of husbands (65%) identified that they had no friends who supported them in their care giving effort.

Twenty husbands (28%) related that even where they received support from relatives and friends, ease of contact was ‘Very’ to ‘Quite difficult’. Importantly, more than one quarter of the group (28%) stated that they did not have a specific person to share their most personal thoughts and feelings with. However, twenty-six (37%) identified that even where there was someone who was available to share with, the person was not always readily available. Most husbands (89%) lived alone with their wives and identified themselves as the primary carer.
Religious beliefs and practices for many people may be an important source of support. Although a high proportion of husbands (77%) reported that they had a religious affiliation, only just over a quarter of the group (27%) identified that religious beliefs and practices were an important source of support ‘Mostly’ or ‘Totally’ in relation to caregiving. In contrast to this finding, one of the items in the Jaloweic Coping Scale (Jaloweic et al., 1984) was “Pray; trust God” and interestingly, nearly two thirds of husbands (63%) related that they used this coping strategy ‘Almost always’ or ‘Often’.

A small number of husbands (6%) identified that relatives and friends attended support groups regularly with them. Number of meetings attended by husbands ranged from one to twenty-four (Table 7.1).

6.7 Cluster Seven: Supports: Support Groups

At the time of interview more than two-thirds (68%) of husbands at the time of interview were attending a support group. Interestingly, a higher proportion of Australian born (42%) compared to overseas born (22%) were attending a group. A high proportion of husbands (87%) stated that groups were ‘Mostly’ or ‘Very helpful’ in providing knowledge/information to assist them in the care giving role. A smaller proportion of husbands (70%), although still a reasonably high number, reported that the group was ‘Mostly’ or ‘Very helpful’ in providing emotional support. Cross tabulation analysis of number of support groups attended by
emotional support indicated that those husbands who had attended less than eleven groups reported that they received less help emotionally.

Support groups provided many benefits to sole carers and family members of people with dementia, assisting as they do with information and guidance on management and self-care strategies for the carer. It may be the nature of support group attendance that once particular aspects of support have been provided, the individual’s need for them drops away. Alternatively, individual expectations of the support group’s ability to assist may not be fulfilled.

Table 6.1

<table>
<thead>
<tr>
<th>No. of groups attended</th>
<th>Percentage of husbands</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-6</td>
<td>31.66%</td>
</tr>
<tr>
<td>7-11</td>
<td>36.66%</td>
</tr>
<tr>
<td>12-24</td>
<td>31.66%</td>
</tr>
</tbody>
</table>

From the table it can be observed that an equal number of husbands attended six or fewer groups and more than twelve groups and slightly more husbands attended between seven and less than twelve groups. On average, husbands had attended 11.5 groups. Husbands were also asked if support groups met their expectations (Table 6.2).
Table 6.2

Extent To Which Support Groups Met Husbands’ Expectations

<table>
<thead>
<tr>
<th>Extent to which support groups met husbands’ expectations</th>
<th>Number of husbands</th>
<th>Percentage of husbands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time</td>
<td>27</td>
<td>37.5</td>
</tr>
<tr>
<td>Some of the time</td>
<td>14</td>
<td>19.4</td>
</tr>
<tr>
<td>Very little of the time</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>None of the time</td>
<td>3</td>
<td>4.2</td>
</tr>
<tr>
<td>Too soon to tell</td>
<td>7</td>
<td>9.7</td>
</tr>
</tbody>
</table>

As the table illustrates, over a third of the group reported that support groups met husbands’ expectations ‘Most of the time’. Almost 20% identified that groups had met their expectations ‘Some’ or ‘Very little’ of the time and a small number of husbands (just over 4%) indicated that support groups had not met their expectations any of the time.

Husbands who were attending a support group reported that they liked the staff (for example, *their friendliness, helpfulness, sympathy shown and offers of help, offers of telephone help*), other carers (for example, *their friendliness, offers of help, understanding, support, ideas provided*), specialist input and information provided and the opportunity to discuss what they were experiencing in a supportive environment. They also highlighted that attendance provided an
opportunity to *talk things out* and express how they were feeling about what they were experiencing, also that group attendance provided an opportunity to go out.

Some criticisms of support groups identified by husbands included: *not enough time for questions, individual carers dominating the group, poor quality of guest speakers, too few male carers attending, didn’t provide support, didn’t meet often enough*, and several husbands reported that listening to others highlighted the progressive nature of the disease and made them feel depressed, sad and distressed.

Questions 48 to 51 provided husbands with an opportunity to provide information about community supports and services. Information about this is examined in the next section.

6. 8 Community Supports and Services

Specifically these questions probed the following issues: Husbands’ knowledge of services and supports available to them in their care giving responsibilities and extent to which they made use of them; which services husbands’ used and how often; types of community services that would provide most assistance in relation to husbands’ care giving; reasons why services were not used.

Just over a third of husbands were informed about supports and services which
could provide assistance with care. Three services that husbands reported knowing about were home care, day care, and hospital and community aged care services (Table 6.3).

Table 6.3

Husbands’ Knowledge of Available Supports and Services

<table>
<thead>
<tr>
<th>Supports &amp; Services</th>
<th>Number of Husbands</th>
<th>Percentage of Husbands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care</td>
<td>9</td>
<td>13%</td>
</tr>
<tr>
<td>Day care</td>
<td>8</td>
<td>11%</td>
</tr>
<tr>
<td>Hospital &amp; community aged care services</td>
<td>7</td>
<td>10%</td>
</tr>
</tbody>
</table>

Further analysis of the data suggested that in a smaller numbers of husbands knew about a range of other services including community nursing services, meals-on-wheels, respite care, transport assistance, support groups, home modification and maintenance, technical aids for disabled, and aged care units, but hadn’t necessarily used them at the time of interview. Reasons provided for this included I manage; not necessary; too busy to find out; not required as yet; at right time will use. Where husbands used services, the three most commonly used services were day care, home care, community nursing and community services (Table 6.4).
Table 6.4

<table>
<thead>
<tr>
<th>Services Utilised by Husbands</th>
<th>Number of Husbands</th>
<th>Percentage of husbands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care</td>
<td>17</td>
<td>24%</td>
</tr>
<tr>
<td>Home care</td>
<td>12</td>
<td>17%</td>
</tr>
<tr>
<td>Community nursing service</td>
<td>10</td>
<td>14%</td>
</tr>
<tr>
<td>Community services</td>
<td>9</td>
<td>13%</td>
</tr>
<tr>
<td>Respite care</td>
<td>8</td>
<td>11%</td>
</tr>
<tr>
<td>Support group</td>
<td>7</td>
<td>10%</td>
</tr>
</tbody>
</table>

From the table it is clear that the service most utilised was day care (24% of husbands). This finding is consistent with the finding in stage one in which carers identified that day care was the most helpful service for the situation they found themselves in. Between 10% and 17% of respondents to the question highlighted that they utilised home care, community services, respite care and support groups. In addition, a few husbands (up to 7% of respondents) reported utilising meals-on-wheels, home modification and maintenance services, hospital aged care service, extended care, Physical Aids for Disabled Persons, accommodation, hearing and speech service, transport, and physiotherapy. The small number of husbands utilising meals-on-wheels is consistent with the findings in stage one of the study. Of those husbands who used services, 44 (62%) reported using them ‘Regularly’. One of the objectives of the study was to identify services that husbands would
find useful and supportive of their care giving activities (Table 6.5) although at the time of interview they were not using them.

<table>
<thead>
<tr>
<th>Services</th>
<th>Number of husbands</th>
<th>Percentage of husbands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite care</td>
<td>18</td>
<td>25%</td>
</tr>
<tr>
<td>Home care; housekeeper</td>
<td>9</td>
<td>13%</td>
</tr>
<tr>
<td>Day care</td>
<td>5</td>
<td>7%</td>
</tr>
<tr>
<td>Nursing service</td>
<td>4</td>
<td>6%</td>
</tr>
</tbody>
</table>

Table 6.5

Respite care, home care, day and nursing service were the four most important services that husbands reported that they would find useful to them in relation to their care giving. Other husbands who responded to the question (up to 6% of respondents), identified that support groups, supervised outings for wife, counselling on wife’s hygiene, help with meals, home maintenance and repair, permanent carer, unpaid volunteer to help and community options would be useful. It is possible that individual husbands indicated more than one service.

6.9 Husbands’ Three Most Important Needs

Husbands were also asked to identify their three most important needs related to
their caregiving role. A range of responses were obtained (Table 6.6).

Table 6.6

Husbands’ Most Important Needs

<table>
<thead>
<tr>
<th>Most important needs</th>
<th>Number of husbands</th>
<th>Percentage of husbands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Few hours off a week; rest; a break; quiet &amp; peace; to relax; time for self; more time alone</td>
<td>24</td>
<td>34%</td>
</tr>
<tr>
<td>Physical health; keep fit</td>
<td>8</td>
<td>11%</td>
</tr>
<tr>
<td>Other company; outside contacts; someone to talk to; keeping in touch with friends; opportunities to socialise</td>
<td>7</td>
<td>10%</td>
</tr>
<tr>
<td>Being understood by others</td>
<td>7</td>
<td>10%</td>
</tr>
</tbody>
</table>

Of those husbands who responded to this question, husbands’ three most important needs were identified as follows: (1) respite care, (2) opportunity to attend to health and fitness needs, and (3) need for company of others, being understood by others. In addition, husbands also indicated that they needed more financial support from government; kindness and consideration from others; sex; help with care giving role, and good night’s rest. It is possible that individual husbands indicated more than one need.

By far, husbands’ most important need was for respite from care giving responsibilities as this would allow them to take a rest from care giving activities and responsibilities, provide time out from wives’ demands on their attention and
allow them to do other things. Of lesser importance was a perceived need to keep healthy and fit. This need is understandable when we remember that care giving places undue physical as well as emotional demands on the caregiver. From the data, husbands did not always feel that they were understood by others. As they did not elaborate on this response it could be proposed that they might have felt unsupported by family and others. There was certainly evidence presented earlier in this chapter to confirm this interpretation. Opportunities to socialise with others, keep in touch with friends, including opportunities to talk with others, were also identified by husbands as important needs.

6. 10 Cluster Eight: Characteristics of Wives’ Condition

Changes in wives’ behaviour had been noted by husbands for between one and over fourteen years (Table 6.7).
Table 6.7

Length of Time Changes Have Been in Evidence

<table>
<thead>
<tr>
<th>Length of time changes have been in evidence</th>
<th>Number of husbands reporting changes</th>
<th>Percentage of husbands reporting changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 to 3 years</td>
<td>22</td>
<td>31%</td>
</tr>
<tr>
<td>4 to 6 years</td>
<td>31</td>
<td>43.7%</td>
</tr>
<tr>
<td>7 to 10 years</td>
<td>13</td>
<td>18.3%</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>5</td>
<td>7%</td>
</tr>
</tbody>
</table>

Nearly seventy-five percent of husbands reported that they had noted changes in wives’ behaviour for between one and six years duration. Moreover, 25% of husbands identified that they had noticed changes in their behaviour for seven or more years. Sixty-six percent of wives were reported by their spouses to have been diagnosed with dementia between one and three years prior to interview. We can conclude that there is a discrepancy between these two figures with more cases of diagnosed dementia than reported changes in wives’ behaviour noted by husbands. Possibly husbands had forgotten how long changes had been in evidence.

In response to a question about the progress of their wives’ dementing illness, husbands described it as gradual (49.3%) or moderate (50.7%) but not rapid. This highlights the progressive nature of the illness and that many husbands would
have to provide care or had been providing care over a considerable period of time.

From the data arising from an analysis of the Clinical Dementia Rating Scale (CDRS) (Berg, 1988), it was clear that wives had significant problems associated with their illness (Table 6.8).

### Table 6.8

<table>
<thead>
<tr>
<th>Changes in Behaviour</th>
<th>Moderate-severe</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory</td>
<td>87%</td>
<td>23%</td>
</tr>
<tr>
<td>Judgment; Problem Solving</td>
<td>87%</td>
<td>39%</td>
</tr>
<tr>
<td>Community involvement</td>
<td>86%</td>
<td>39%</td>
</tr>
<tr>
<td>Simple chores; restricted interests</td>
<td>70%</td>
<td>32%</td>
</tr>
<tr>
<td>Orientation</td>
<td>54%</td>
<td>27%</td>
</tr>
<tr>
<td>Personal care; incontinence</td>
<td>35%</td>
<td>25%</td>
</tr>
</tbody>
</table>

From the table it can be concluded that the three most significant changes in wives’ behaviour were memory loss, changes in judgment and problem solving ability and decreased community involvement at the moderate to severe level of functioning. In addition, many wives were also experiencing severe changes in other aspects of their behaviour. The finding that memory loss was one of the most significant changes in wives’ behaviour was highlighted in stage one.
6.11 Summary

This chapter has provided a descriptive analysis of cluster data of relevance to husbands’ experience of burden and depression, and concludes with a summary of pertinent findings from the second stage of the study.

Descriptive findings in Stage Two of the study indicated that husbands’ and wives’ ages were similar (73.93 and 73.66) and they lived together in their own houses, home unit or flat and had been married for many years. Just over one-third of husbands and less than one third of wives had been born overseas. Husbands were by-and-large better educated than wives who had spent most of their married lives at home as wives and mothers. More than half of the husbands reported that their main source of income was a pension. Nearly all the group identified spending between 10 and 24 hours care giving daily with over one third providing 24 hour care. Just over one fifth of husbands identified that care giving bore similarities to the job or jobs that they used to do. In this regard similarities identified emphasised decision making, educational, supervisory and planning roles and activities in relation to providing care and suggests that male’s model of care giving was located back in their workforce experiences. Moreover, a high proportion emphasised the need to be efficient and organised in relation to their care giving responsibilities on a day-to-day basis.

A similar proportion of husbands related that they had a close relationship with
their wives. However, further questions, investigating the effects of care giving on the relationship, revealed that several husbands identified that their feelings towards their wives had changed since the onset of the problems associated with their illness. This finding was also identified in stage one interview data. These changes were related to the impact of wives’ behaviours associated with the progressive nature of the disease on husbands and changes in feelings towards wives were associated with their own reactions to care giving and changes in their own health status. Several husbands, however, reported that care giving had been a positive experience for them.

Over 25% of the group reported that they lacked any support from relatives or friends or didn’t have a specific person to share personal thoughts and feelings with in relation to care giving. Even where support was available, ease of contact was difficult or not readily available to provide any form of assistance. Religious beliefs and practices were important sources of support for just over 25% of husbands although a somewhat larger group of husbands resorted to prayer and putting their trust in God as reported earlier in this chapter.

At interview, over two thirds of husbands were attending a support group. Moreover, twice as many husbands who were born in Australia attended support groups compared to those who had been born overseas. Husbands reported that groups provided more educational than emotional support although there was some evidence to support the notion that the latter might have increased as
husbands attended more groups. Few relatives or friends attended groups with husbands. If support groups attended were held in the daytime, then this finding should not be unexpected. Less than 50% of those husbands attending support groups had their expectations met ‘Most’ or ‘Some of the time’. Specifically, husbands liked staff friendliness, helpfulness and sympathy shown, and carer friendliness, understanding, offers of help and ideas for care giving strategies. Visiting speakers and information was also highlighted, also the opportunity to just go out. Support groups also provided an opportunity to discuss their care giving experiences with others. However, group attendance was not always a positive experience.

Less than two thirds of the group were able to identify a range of support services, however, 59% of those so identifying services had not made use of them at the time of interview. For some, support services were not necessary at the time of interview as they were still able to manage. Others were too busy with care giving and did not have time to identify what was available. Where support services were employed, the most frequently used services were day care, home care, community nursing service, community services, respite care and support groups. For those not using services at the time of interview, the services most anticipated to be helpful in the future were respite care, home care, day care and nursing service. Husbands also identified the need to keep fit and healthy, opportunities to socialise and be understood by others.
Changes in wives’ behaviour were reported by husbands to be present at the time of interview for up to six years although diagnosis had only been made within the past one to three years. According to the informants, the course of their wives’ illness was either gradual or moderate. Most wives had significant memory loss and more than half were significantly disorientated. Many were also experiencing significant impairment in judgment and problem-solving abilities. Most wives had experienced significantly reduced community involvement, however, nearly 40% of wives were able to function outside the home without supervision. Ability to carry out simple chores was also significantly affected for 70% of wives and nearly 30% of husbands reported that wives required a lot of help with personal care and were often incontinent.

Chapter Seven of the thesis provides a descriptive-correlational analysis of the variables of interest from the developed questionnaire and selected standardised measures of care giver burden and depression, reported and described in Chapter Four.
CHAPTER SEVEN

HUSBANDS’ BURDEN AND DEPRESSION:
RESULTS FROM STAGE TWO OF THE STUDY

This chapter examines husbands’ experiences of burden and depression in relation to care giving. Specifically, questionnaire items were developed and standardised measures, used to identify those factors that were associated with the development of psychological distress in relation to husbands’ role as primary carers of wives with dementia.

Introduction

The bulk of this chapter describes stage two of the study where, in relation to providing care for spouses with dementia, a descriptive-correlational research design was used to examine husbands’ experiences of burden and depression. The chapter begins with a summary of stage one study findings which provided justification for the development of stage two.

The stage one study provided data from interviews with sixteen carer informants of their wives. Informants described their present situations, looked back on their experiences and looked forward with trepidation to the future. Using grounded theory and content analysis, the stresses of home-based care giving by husbands where the wife had dementia were traced and described.
During stage one interviews, husbands used a number of emotive terms to illustrate the way care giving was affecting them or the stress that they were experiencing. For example, they reported feeling frustrated, worried, angry, fearful, concerned, disappointed, pressured, irritated, anxious and hurt. These descriptors illustrate both a subjective and objective definition of burden described in Chapter Three. They also reflect a third view of burden, again described in Chapter Three, and favoured in this thesis, as resulting from the tension created competing care giving demands and resultant threats to carers’ ability to meet their basic needs. These findings were seen by the researcher to be consistent with previous research findings suggesting that family carers of people with dementia generally experienced high levels of burden.

From stage one of the study, husbands also identified feeling sad, flat, were easily upset or weepy and tearful and one stated that he had thought of suicide as a way out of the impossible situation he found himself in. These emotions are often expressed by people who are depressed. Many older people, as well as others, may experience depressive symptoms from time to time and some may be clinically depressed. Whilst there appeared to be some anecdotal evidence that older husbands were experiencing symptoms of depression, it was not clear from Stage One findings if any were clinically depressed, the latter requiring further assessment and possibly treatment.
It was postulated that psychological distress might place husbands at risk of physical and mental health problems such as clinical depression, and precipitate early institutionalisation of wives into long-term care. In addition, it was the researcher’s assumption that knowledge of the factors that contributed to husbands’ burden and depression would assist health professionals working with family carers to identify those ‘at risk’, so as to empower them to seek solutions. From these findings, and in consultation with other informed sources, it became clear that since little was known about these phenomena in older husband caregivers and specifically, about their degree of burden and depression, these should be the focus of stage two of the study.

7.1 Recapitulation of Stage One Findings

Stage one findings provided evidence that many husbands were experiencing psychological distress related to a state of tension created by the impact of care giving demands on their ability to meet their own basic needs. In particular, husbands in a sub-group of thirteen spousal pairs described problematic care giving experiences. These included wives’ aberrant behaviour; changes in the spousal relationship; troubling and different nature of the work; having to take on more responsibilities; restrictions on freedom and choice; feelings of failure; a sense of isolation and feelings of loneliness; physical and emotional effects associated with care giving; changes to future plans; having to forego usual activities; effects of care giving on other responsibilities; and husbands’ responses
to the care giving situation. It was hypothesised that these differences impacted on husbands being able to meet their own needs.

7.2. Stage Two of the Study: Analytical Procedures and Decision-Making

Two groups of independent variables were investigated in stage two of the study in relation to their interaction effects on husbands’ burden and depression. These were: (1) variables identified from stage one findings, and (2) other variables identified from further reviews of the literature, discussions with the carers and health professionals working in aged care and aged care psychiatry services and the researcher’s supervisor. The two groups of variables were organized by the researcher into several cluster variables, each representing an aspect of burdensome care giving. Of additional interest were the effects of husbands’ burden and depression on upbringing, previous care giving experiences and work-related experiences.

It was not possible to examine the effects on husbands’ burden and depression of each of the variables identified in Stage One. Consequently, stage two research focused on eight broad issues in the context of husband care giving in female spouse dementia: (1) Husbands’ and wives’ demographics (2) Characteristics of care giver effort (3) Care givers’ perceptions of their role (4) Effects of care giving on husbands (5) Influences on husbands’ role as care giver (6) Support of
relatives and friends, religious beliefs and practices (7) Support group attendance, and (8) Characteristics of wives’ condition.

In examining these issues, variables of interest were grouped into eight clusters, as described in Chapter Four, each representing the issues of interest. Each is briefly described.

1) *Husbands’ and wives’ demographics:* Questionnaire items included age; country of birth; highest level of education; religious affiliation; main source of income; place of residence – became Cluster One variables;

2) *Nature of the care giving work:* Questionnaire items were percentage of care giving responsibilities; hours in direct and indirect care – became Cluster Two variables;

3) *Carers’ perception of role:* Questionnaire items included care giving seen as job; seen as being like a job used to do; relevance of experiences in previous job to present role; importance of being organised and efficient; and care giving seen as being important – became Cluster Three variables;

4) *Changes in spousal relationship:* Questionnaire items included effects of care giving on relationship; changes in feelings towards spouse; closeness of relationship – became Cluster Four variables;

5) *Physical and emotional health:* Questionnaire items included changes in husbands’ physical and emotional health status – became remainder of
Cluster Four variables;

6) *Influences on husbands’ role as care giver:* Questionnaire items were extent to which upbringing and previous experiences prepared husbands for the role – became Cluster Five variables;

6) *Sense of isolation and feelings of loneliness:* Questionnaire items included number of friends providing support; other household residents; specific person to share with; religious beliefs and practice – became Cluster Six variables;

7) *Supports: Support Group Attendance:* Questionnaire items included attendance at support group; support group met expectations; number of meetings attended; helpfulness of group providing knowledge and emotionally; others attending group with carer – became Cluster Seven variables;

8) *Wives’ behaviour:* Problem Behaviour Checklist (Zarit et al., 1980) and questionnaire items related to severity of illness; and course of illness - became Cluster Eight variables.

Standardised measures of burden and depression were utilized to confirm or disconfirm earlier findings in stage one of the study that husbands were experiencing a sense of burden and some were depressed. Several other measures were identified for inclusion in the study after discussions with the researcher’s supervisor. As described earlier, identified questionnaire items were organized
into eight clusters to facilitate the analysis and reduce the potential problems associated with analysing a large number of variables of interest in relation to a small sample size. Clusters One to Seven comprised husbands’ characteristics of interest and Cluster Eight related to wives’ characteristics associated with their illness. These were described in Chapter Four.

As described in Chapter Four, in this present study multiple regression was used to analyse the collective and separate contributions of the eight cluster variables (the independent variables) to the variation of husbands’ burden and depression scores (the dependent variables) so as to predict the changes in the dependent variables in response to changes in the independent variables.

The data were examined for normality and multicollinearity. A visual check of the histograms for each significant variable, when regressed on burden and depression, revealed that the data distribution closely followed the diagonals thus allowing the researcher to feel confident that all statistical results were valid (Hair et al., 1995). In addition, it was pointed out in Chapter Four that a variance factor (VIF) of over 10 was used to reduce the possibility that each independent variable was explained by other independent variables. Similarly, a condition index (CI) greater than 30 represents a high degree of collinearity, cluster variables, therefore, when regressed on the dependent variables with a VIF over 10 or a CI over 30 (Dupont, 2002), were omitted from the derived models of prediction of burden and depression. Variables were also excluded from the model where
squared multiple correlations of variables were .99 to .9999 as proposed by Tabachnick & Fidell (1996).

7.3 Husbands’ Burden and Depression Levels

As described in Chapter Four, the degree of husbands’ burden was measured utilising the 22-item Zarit Burden Scale (ZBS), as developed by Zarit et al. (1980). This scale had been utilised by the researcher in several other studies of family carers’ burden related to care giving. The scale comprises a list of statements which reflect how carers sometimes feel when taking care of another person. After each statement carers were required to indicate how often they felt that way (Never, Rarely, Sometimes, Quite Frequently and Nearly Always). In addition, the Beck Depression Inventory (Beck et al., 1961) (also described in Chapter Four) was utilised to determine whether any of the husbands were depressed.

The following findings report husbands’ burden and depression levels and the contributions of the cluster variables of interest to these phenomena. Findings in relation to husbands’ burden levels regressed on the cluster variables are discussed first. Findings for husbands’ depression levels are presented later in the chapter.
7. 3. 1 Husbands’ Burden Levels

As stated earlier, husbands’ burden levels were examined using the 22-item Zarit Burden Scale (Zarit et al. 1986). Descriptive analysis of the data is presented in Table 7.1.

Table 7.1

Husbands’ Burden Levels

<table>
<thead>
<tr>
<th>Extent of Burden</th>
<th>Score</th>
<th>No. of Husbands</th>
<th>Percentage of Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>None to rarely</td>
<td>0-43</td>
<td>14</td>
<td>20%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>44 – 65</td>
<td>41</td>
<td>58%</td>
</tr>
<tr>
<td>Quite frequently to Nearly always</td>
<td>66 – 110</td>
<td>16</td>
<td>22%</td>
</tr>
</tbody>
</table>

From the table, a high proportion (80%) of husbands reported feeling burdened some to much of the time. Significantly, nearly a quarter of the group identified feeling burdened quite frequently.

As reported earlier in this chapter, with a small sample size and a large number of variables of interest to the researcher, it was necessary to overcome these problems by organising the independent variables into eight variable clusters and each was given a descriptive title to capture their focus. Clusters comprised between four and eleven variables and these were described in Chapter Four. Each of the cluster variables was then regressed on husbands’ burden scores using stepwise regression.
7.3.2 Multiple Regression Analysis of Cluster Variables with Husbands’ Burden Scores: Procedure Followed

In the present study, the stepwise regression method was employed to identify those variables in each cluster that were significantly correlated with husbands’ burden scores, that is, the variable or variables that made the largest contribution to $R^2$, allowing the researcher to identify the proportion of variance of husbands’ burden scores that were explained by the model derived from the regression analysis (Minichiello et al., 2004).

After discussion with the researcher’s supervisor it was decided that for the purposes of the regression analysis, variables were included from the regression model with a probability of 0.25 or less as important variables were less likely to be excluded from the regression model. This figure was arrived at because of the large number of variables involved and to account for a study that did not use an experimental design or randomisation procedures. After the cluster variables were regressed on husbands’ burden and depression scores, only those reaching significance at 0.05 or less were accepted.

The following provides a description of the results when the eight cluster variables were regressed on husbands’ burden scores and is reported in tables. Following the same procedures, results for husbands’ depression will be reported later in this chapter. Questionnaire items will be identified as Q1, Q2 etc.
Cluster One Variables: Husbands’ and Wives’ Demographics

As described in Chapter Four, Cluster One comprised nine demographic variables for husbands and their wives. Husbands’ and wives’ demographic variables included age (Q1), country of birth (Q2), highest level of education (Q4), religion (for husbands only), (Q5) main source of income (Q11), and husbands’ place of residence (rural/metropolitan). Each cluster variable was regressed on husbands’ burden scores and the demographic variables that were significantly correlated with husbands’ burden are identified in the table that follows.

Table 7.2

Multiple Regression Analysis with Burden Regressed on Husbands’ and Wives’ Demographic Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wives’ age</td>
<td>-.215</td>
<td>-1.760</td>
<td>.083</td>
<td>.046</td>
<td>1.000</td>
<td>23.177</td>
</tr>
<tr>
<td>Husbands’ main source of income</td>
<td>-.178</td>
<td>-1.465</td>
<td>.148</td>
<td>.078</td>
<td>1.007</td>
<td>28.704</td>
</tr>
</tbody>
</table>

The results of the analysis indicate that there were two predictive models of
husbands’ burden. In Model One, wives’ age contributed 4.6% of the variance of burden and in model two husbands’ main source of income contributed a further 3.2%. After examining the group means and as these variables were negatively correlated with burden, older husbands who were providing care for younger wives and husbands who reported that they received a pension (Age or Veterans or other Pension) as their main source of income experienced greater burden.

For each succeeding analysis of Clusters Two to Eight variables these two significant demographic variables were introduced first into the regression equation as moderator variables so as to determine the unique contribution of $R^2$ to each significant cluster variable over and above that of the significant demographic variables. In other words, in the results that follow an account has been taken of the contribution of both burden and depression of the two significant, fundamental demographic variables.

**Cluster Two Variables: Characteristics of Care giving Effort**

Cluster Two variables comprised percentage of health care costs (Q12), care giving responsibilities (Q13), hours in direct and indirect care (Q14), and length of time providing care (Q15). When each of the variables was entered into the regression equation with husbands’ burden scores, significant variables correlated with burden were hours daily providing direct care, and percentage of health care costs paid by husbands. When the significant demographic variables were entered
as moderator variables none of the original significant variables remained in the model indicating that none of the cluster variables made a unique contribution to burden over and above the contribution made by the significant demographic variables.

**Cluster Three Variables: Husbands’ Perceptions of their Role**

There were five variables in Cluster Three. These were care giving perceived as a ‘job’ (Q42); perceived like job used to do (Q43); experiences in previous job (Q45); important to be organised and efficient (Q46) and care giving seen as being important (Q47). When these variables were regressed on husbands’ burden scores, care giving perceived as a ‘job’, seen as being important, and important to be organised and efficient, were found to be significantly correlated with burden. Husbands’ main source of income left the model, with care giving perceived as a ‘job’ and wives’ age remaining in the new model (Table 7.3) when the demographic variables were entered into the equation as moderator variables.
Table 7.3

Multiple Regression Analysis with Burden Regressed on Husbands’ Perceptions of their Role

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care giving perceived as a ‘job’</td>
<td>.492</td>
<td>4.694</td>
<td>.000</td>
<td>.231</td>
<td>1.000</td>
<td>4.122</td>
</tr>
<tr>
<td>Wives’ age</td>
<td>-.138</td>
<td>-1.282</td>
<td>.204</td>
<td>.238</td>
<td>1.070</td>
<td>28.330</td>
</tr>
</tbody>
</table>

The unique contribution of the cluster variable was 23.1% of the variance of burden and since it was positively correlated with burden, the more care giving was perceived as a ‘job’ the greater the burden experienced by husbands in the study.

Cluster Four Variables: Effects of Care giving on Husbands’ Burden Scores

Cluster Four variables included closeness of emotional relationship (Q6), changes in physical health status (Q16), emotional health status (Q17), feelings towards spouse (Q18) and effect of care giving on the relationship (Q37).

When all cluster variables were regressed on burden, changes in husbands’ emotional health status and effects of care giving on the husband-wife relationship
were found to be significantly correlated with burden. Following the usual procedure of entering the significant demographic variables into the regression equation as moderator variables, the initial significant variables remained in the new model (Table 7.4).

Table 7.4

Multiple Regression Analysis with Burden Regressed on Effects of Care giving

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted $R^2$</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in emotional health status</td>
<td>.474</td>
<td>4.470</td>
<td>.000</td>
<td>.225</td>
<td>1.000</td>
<td>4.267</td>
</tr>
<tr>
<td>Effects of care giving on Relationship</td>
<td>.357</td>
<td>3.492</td>
<td>.001</td>
<td>.343</td>
<td>1.078</td>
<td>5.183</td>
</tr>
</tbody>
</table>

From the table, changes in emotional health status accounted for 22.5% of the variance of burden and effects of care giving on the relationship contributed a further 11.8%. As the significant variables were positively correlated with burden, husbands who experienced increasing changes in their emotional health
status and their relationship experienced more burden.

Cluster Five Variables: Influences on Husbands’ Role as Care giver

Cluster Five comprised nine variables. These were:

- extent to which upbringing prepared husband for care giving role (Q34),
- extent to which previous experiences providing care prepared husband for role of care giver (Q40),
- personality traits (Bem’s Sex Role Inventory (Bem, 1974) – comprised two variables being Instrumental and Affective Traits),
- coping strategies (Jalowiec’s Coping Strategies Scale – comprised four variables, being Problem-solving; Reframing; Avoidant-Evasive and Regressive Coping Strategies), and
- husbands’ experiences in previous job (Q45).

When each of these variables was regressed on husbands’ burden scores, the following four were found to be significantly correlated with burden: avoidant-evasive coping strategies, affective personality traits, regressive coping strategies, and problem-solving strategies. After the significant demographic variables entered the equation, regressive coping strategies exited from the model (Table 7.5).
Table 7.5

Multiple Regression Analysis with Effects of Care giving Regressed on Husbands’ Burden

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R2</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive coping strategies</td>
<td>.445</td>
<td>4.124</td>
<td>.000</td>
<td>.198</td>
<td>1.000</td>
<td>7.282</td>
</tr>
<tr>
<td>Affective personality traits</td>
<td>-.328</td>
<td>-3.201</td>
<td>.002</td>
<td>.303</td>
<td>1.022</td>
<td>14.680</td>
</tr>
<tr>
<td>Problem solving coping strategies</td>
<td>-.332</td>
<td>-3.539</td>
<td>.001</td>
<td>.386</td>
<td>1.002</td>
<td>27.882</td>
</tr>
</tbody>
</table>

As the table demonstrates, the unique contribution of the cluster variable avoidant-evasive coping strategies was 19.8% of the variance of burden, with affective personality traits, and problem solving coping strategies contributing an additional 18.8%. It can also be noted that increased use of avoidant-evasive strategies was positively correlated with burden, therefore, indicating that husbands who used more avoidant-evasive coping strategies experienced more burden. Since affective personality traits and problem-solving strategies were negatively correlated with burden, husbands scoring low on affective traits and those using fewer problem-solving coping strategies experienced more burden.
Cluster Six Variables: Supports: Relatives and Friends and Religious Beliefs & Practices

As described in Chapter Four, Cluster Six comprised number of relatives and friends providing support (Q29), ease of contact with relatives and friends (Q30), specific person to share with (Q31), other household residents (Q8), and religious beliefs and practices (Q33).

When Cluster Six variables entered the regression equation the following were significantly correlated with burden: other household residents; number of relatives providing support and number of friends providing support. When the significant demographic variables were entered into the equation as moderator variables, all of the independent variables were excluded from the new model along with husbands’ main source of income, while wives’ age remained in the model. It can be concluded that none of the Cluster Six variables made a unique contribution to burden over and above wives’ age.

Cluster Seven Variables: Supports: Support Group Attendance

Cluster Seven variables were attending support group (Q21); how helpful group was in provision of knowledge/information (Q22); providing emotional support (Q23); number of relatives and friends attending group with carer (Q24); number of groups attended (Q25). Findings in this chapter indicated that support group
When the cluster variables were entered into the regression equation the only significant Cluster Seven variable was ‘attending a support group’ but when the demographic variables entered the regression equation as moderator variables, ‘attending a support group’ left the new model. It may be concluded that none of the cluster variables made a unique contribution to burden over and above the contribution made by the significant demographic variables.

**Cluster Eight Variables: Characteristics of Wives’ Condition**

When Cluster Eight variables, length of time changes had been recognised (Q59), Problem Behaviour Checklist (Zarit et al., 1980); Clinical Dementia Rating Scale (Berg, 1988); length of time since diagnosis (Q61), and course of wives’ illness (Q63) were regressed on burden, the significant variables were problem behaviours, course of illness, and length of time changes in behaviour had been recognised. Upon entering the significant variables first into the equation as moderator variables, problem behaviours remained in the new model along with wives’ age and husbands’ main source of income.
Table 7.6 indicates that the unique contribution of the cluster variable ‘problem behaviours’ was 10.6% of the variance of husbands’ burden. Although problem behaviours was negatively correlated with burden, when the mean was examined it was evident that husbands experienced greater burden when wives experienced more problem behaviours.

7.4 Significant Variables from all Clusters

Significant variables from Clusters Three, Four, Five and Eight and husbands’ burden scores were entered into a regression equation to identify each variable’s individual contribution to the variance of burden. Wives’ age and husbands main
source of income’ were entered first as moderator variables (Table 7.7).

### Table 7.7

**Contribution of Significant Variables Regressed on Burden**

<table>
<thead>
<tr>
<th>Model Number</th>
<th>Predictive Models of Burden</th>
<th>Cumulative Adjusted $R^2$</th>
<th>Cumulative %age of Variance of Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Care giving perceived as a ‘job’</td>
<td>.242</td>
<td>24.2%</td>
</tr>
<tr>
<td>2</td>
<td>Effects of care giving on relationship</td>
<td>.373</td>
<td>13.1%</td>
</tr>
<tr>
<td>3</td>
<td>Avoidant-evasive coping strategies</td>
<td>.503</td>
<td>13.0%</td>
</tr>
<tr>
<td>4</td>
<td>Problem solving coping strategies</td>
<td>.551</td>
<td>4.8%</td>
</tr>
<tr>
<td>5</td>
<td>Affective personality traits</td>
<td>.593</td>
<td>4.2%</td>
</tr>
<tr>
<td>6</td>
<td>Changes in emotional health status</td>
<td>.597</td>
<td>.4%</td>
</tr>
<tr>
<td>7</td>
<td>Wives’ age</td>
<td>.600</td>
<td>.3%</td>
</tr>
</tbody>
</table>

In Model One, care giving perceived as a ‘job’ contributed 24.2% to the variance of burden. In addition, model two, effects of care giving on relationship, contributed a further 13.1% followed closely by avoidant-evasive coping strategies.
strategies in model three (13%). Moreover, models one, two and three contributed over 50% of the variance of husbands’ burden whilst models four to seven contributed less than 10%.

To ensure that no significant variables were missed all non-significant variables from the eight clusters were then regressed on burden. The analysis indicated that no significant variables had been missed.

7.5 Interaction Effects of Combined Independent Variables with Burden

There were no studies in the literature review that examined the interactive effects of independent variables regressed on burden - the dependent variable of interest - in relation to care giving generally and care giving by older husbands of wives with dementia in particular. It was not possible in this study to examine all interactive effects of the variables of interest with burden. From the previous regression analysis (Table 7.7) it is clear that care giving perceived as a ‘job’ together with effects of care giving on the relationship and use of avoidant-evasive coping strategies contributed over 50% of the variance of burden. It seemed a reasonable approach therefore, to include these variables in the interaction analysis and to exclude those contributing less than 10%. Moreover, the researcher, therefore, sought to identify the contribution of other cluster variables in combination with each of these three significant variables to husbands’ burden scores. Clearly, it was not possible to do this with the large
number of variables involved. After reviewing all cluster variables, it was evident that there were a number of variables that were significantly correlated with burden when combined with care giving perceived as a ‘job’. Although various possible significant correlations were noted, only those combinations that contributed over 20% of the variance of burden are reported here.

(1) Care giving Perceived as a ‘Job’

Care giving perceived as a ‘job’ was combined with several cluster variables to examine if there were any interaction effects when regressed on burden. Several variables were selected from Clusters Three and Four. The researcher hypothesised that husbands who perceived care giving as ‘another’ job and at the same time were experiencing adverse effects on the relationship associated with care giving, changes in their feelings toward spouses and believed that it was important to be efficient and organised, experienced greater burden. The researcher then proceeded to test these hypotheses. Firstly, care giving perceived as a ‘job’ was combined with care giving has affected relationship with spouse (from Cluster Four) and regressed on burden. The combined variables were significantly correlated with burden and accounted for 37.9% of the variance of burden (see Table 7.8). Husbands, therefore, who increasingly perceived care giving as a ‘job’ and who felt that their relationship had deteriorated, experienced more burden.
Table 7.8

Interaction Effects of Care giving Perceived as a ‘Job’
and Care giving Affected Relationship with Spouse Regressed on Burden

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care giving seen perceived as a ‘job’ and care giving</td>
<td>.623</td>
<td>6.614</td>
<td>.000</td>
<td>.379</td>
</tr>
<tr>
<td>has affected relationship with spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care giving has affected</td>
<td>.458</td>
<td>4.285</td>
<td>.000</td>
<td>.199</td>
</tr>
<tr>
<td>relationship with spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Secondly, care giving seen perceived as a ‘job’ was combined with feelings have changed towards spouse (a Cluster Four variable). The combined variables were significantly correlated with burden and accounted for 27.3% of the variance of burden (Table 7.9).
Table 7.9

Interaction Effects of Care giving Perceived as a ‘job’ and Feelings Have Changed Towards Spouse Regressed on Burden

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care giving seen perceived as a ‘job’ and feelings have changed towards spouse</td>
<td>.522</td>
<td>5.089</td>
<td>.000</td>
<td>.273</td>
</tr>
<tr>
<td>Feelings have changed towards spouse</td>
<td>.302</td>
<td>2.633</td>
<td>.010</td>
<td>.078</td>
</tr>
</tbody>
</table>

As the combined variables were positively correlated with burden, those husbands who increasingly perceived care giving as a ‘job’ and whose feelings towards their spouse had changed, experienced greater burden.

(2) Effects of Care giving on the Husband-Wife Relationship

In this section the effects of care giving on the husband-wife relationship combined with various cluster variables when regressed on burden was examined. After reviewing all clusters, variables were selected by the researcher from Clusters Four and an item from Barriers to Care giving Index (Kaye & Applegate,
and combined with effects of care giving on the husband-wife relationship. The researcher hypothesised that effects of care giving on the husband-wife relationship combined with changes in spouses’ personality, feelings toward spouse associated with care giving (an item from Barriers to Care giving Index) (Kaye & Applegate, 1990a.), use of more avoidant-evasive coping strategies, and changes in feelings toward spouse, would result in more burden. These hypotheses were then tested.

Firstly, effects of care giving on husband-wife relationship was combined with changes in wives’ personality (an item from Barriers to Care giving Index) (Kaye & Applegate, 1990a.) and regressed on burden.

From Table 7.10, above, the combined variables accounted for 37.4% of the variance of burden. As these variables were positively correlated with burden,
husbands’ burden levels increased in association with care giving continued to impact on the relationship and where spouses experienced continuing personality changes.

Secondly, effects of care giving on husband-wife relationship combined with avoidance-evasive coping strategies (a Cluster Five variable) accounted for 26.3% of the variance of burden (Table 7.11).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effects of care giving on relationship &amp; avoidant-evasive coping strategies</td>
<td>.523</td>
<td>5.103</td>
<td>.000</td>
<td>.263</td>
</tr>
<tr>
<td>Avoidant-evasive coping strategies</td>
<td>.445</td>
<td>4.124</td>
<td>.000</td>
<td>.186</td>
</tr>
</tbody>
</table>

From the table, it will be seen that combined variables were positively correlated with burden as the effects of care giving on the relationship increased and husbands were utilising more avoidant-evasive coping strategies, more burden was experienced.
Thirdly, effects of care giving on the husband-wife relationship was combined with feelings changed towards spouse (from Cluster Four) and regressed on burden (Table 7.12). From the table the reader will note that these variables were significantly correlated with burden and accounted for 20.3% of the variance of burden.

Table 7.12
Interactive Effects of Care giving on the Husband-Wife Relationship and Feelings Changed Toward Spouse Regressed on Burden

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effects of care giving on relationship &amp; feelings changed towards spouse</td>
<td>.463</td>
<td>4.340</td>
<td>.000</td>
<td>.203</td>
</tr>
<tr>
<td>Feelings changed towards spouse</td>
<td>.302</td>
<td>2.633</td>
<td>.010</td>
<td>.078</td>
</tr>
</tbody>
</table>

As both variables were positively correlated with burden, husbands experienced more burden as effects of care giving on the relationship increased and feelings continued to change towards their spouses.
(3) Avoidant-Evasive Coping Strategies

Avoidant-evasive coping strategies were regressed on burden in combination with variables from Clusters Three and Four the researcher hypothesising that use of avoidant-evasive coping strategies in combination with changes in emotional health status would be associated with greater burden for husbands.

Firstly, from Table 7.13 which follows, it can be observed that avoidant-evasive coping strategies in combination with changes in emotional health status (a Cluster Three variable) was significantly correlated with burden and accounted for 24.5% of the variance of burden. As these variables were positively correlated with burden, husbands who used more avoidant-evasive coping strategies and who at the same time increasingly perceived care giving as a ‘job’, experienced more burden.
Table 7.13

Interactive Effects of Avoidant-Evasive Coping Strategies Combined with Care giving Perceived as a ‘job’ Regressed on Burden

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive coping strategies and care giving perceived as a ‘job’</td>
<td>.506</td>
<td>4.837</td>
<td>.000</td>
<td>.245</td>
</tr>
<tr>
<td>Care giving perceived as a ‘job’</td>
<td>.492</td>
<td>4.694</td>
<td>.000</td>
<td>.231</td>
</tr>
</tbody>
</table>

Secondly, avoidant-evasive coping strategies, in combination with changes in emotional status (from Cluster Four), was also correlated with burden and accounted for 23.6% of the variance of burden (see Table 7.14).
From the table, the combined variables were positively correlated with burden, husbands, therefore, who used more avoidant-evasive coping strategies and experienced continuing changes in their emotional health status experienced more burden.

To summarise, when care giving perceived as a job was combined with theoretically selected cluster variables, the best predictors of burden were care giving has affected relationship with spouse and feelings have changed towards spouse. Moreover, effects of care giving on husband-wife relationship were combined with various cluster variables, changes in spouses’ personality, carers use of avoidant-evasive coping strategies and changes in carers’ feelings towards spouse were the best predictors of burden. Finally, when avoidant-evasive coping
strategies were combined with cluster variables, the best predictors of burden were care giving perceived as a job and changes in carers’ emotional relationship.

The next section of the chapter will examine husbands’ depression levels and determine the contribution of the cluster variables when regressed on husbands’ depression scores.

7.6 Multiple Regression Analysis of Cluster Variables with Husbands’ Depression Scores

In Stage Two, husbands’ experience of depression was measured utilising the 21-item Beck Depression Inventory (BDI) (Beck et al., 1961), as described in Chapter Four. The BDI allows a quantitative assessment of the intensity of the depression that husbands might be experiencing associated with care giving. As described in Chapter Four, for each statement there are four response choices for each category or series of statements rated 0,1,2,3 denoting increasing severity of symptoms. Husbands were required to indicate which response choice was the most accurate one for the past week, including the day on which the measure was completed by them.

From a descriptive analysis of the data derived from administration of the BDI, 39% of husbands were experiencing some degree of depression with 14% reporting that they were experiencing moderate-severe depression (see Table
Table 7.15

Husbands’ Level of Depression

<table>
<thead>
<tr>
<th>Level of Depression</th>
<th>Score on Beck Depression Inventory</th>
<th>No. of Husbands</th>
<th>Percentage of all Husbands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>0-9</td>
<td>43</td>
<td>61.0</td>
</tr>
<tr>
<td>Mild</td>
<td>10-15</td>
<td>18</td>
<td>25.0</td>
</tr>
<tr>
<td>Mild-Moderate</td>
<td>16-19</td>
<td>4</td>
<td>6.0</td>
</tr>
<tr>
<td>Moderate-Severe</td>
<td>20-29</td>
<td>6</td>
<td>8.0</td>
</tr>
<tr>
<td>Severe</td>
<td>30-63</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

To identify those cluster variables that were associated with husbands’ depression, multiple regression analysis was used to examine the collective and separate contributions of the independent variables (the cluster variables) of interest to the variation of the dependent variable (Beck Depression Inventory) (Beck et al., 1961). The reader will remember that as the sample size was small (n=71) and with a large number of variables included in this type of analysis, the same procedure was used as for husbands’ burden and each of the eight variable clusters was regressed on husbands’ depression scores using stepwise regression analysis. Cluster variables regressed on depression with a CI greater than 30 and a VIF of over 10 were omitted from the derived model of prediction of depression. Variables were also excluded where squared multiple correlations of variables were .99 to .9999. These steps were taken and described earlier in this chapter.
Findings will now be described.

Cluster One Variables: Husbands’ and Wives’ Demographic Variables

Cluster One variables comprised nine demographic variables for husbands and wives. These were described in Chapter Four and earlier in this chapter. Each set of cluster variables was regressed on husbands’ depression scores. Consistent with the procedure followed in relation to caregivers’ burden and described earlier in this chapter, the demographic variables were entered into the regression model. From Table 7.16 we can observe that husbands’ religion accounted for 5.8% of the variance of depression and wives’ age an additional 4.6%.

Table 7.16

Multiple Regression Analysis with Depression Regressed on Husbands’ and Wives’ Demographic Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husbands’ religion</td>
<td>.241</td>
<td>1.989</td>
<td>.051</td>
<td>.058</td>
<td>1.0</td>
<td>4.488</td>
</tr>
<tr>
<td>Wives’ age</td>
<td>-.214</td>
<td>-1.793</td>
<td>.078</td>
<td>.104</td>
<td>1.0</td>
<td>27.956</td>
</tr>
</tbody>
</table>
From the table husbands’ religion and depression was positively correlated indicating that husbands who reported that they had a religious affiliation experienced greater depression. This was an unexpected finding but perhaps highlights that even where husbands may have had religious beliefs and been involved in religious practices, these ceased to provide comfort as it became increasingly evident to them that they didn’t assist the care giving challenges in the same way that they used to as wives’ condition continued to deteriorate and they found themselves providing increasing amounts of supervision. In addition, wives’ age was negatively correlated with depression. When the statistical data were examined it was evident that older husbands who were providing care for younger wives were experiencing more depression.

**Cluster Two Variables: Characteristics of Care giver Effort**

Cluster Two variables comprised four characteristics of care giving effort variables as described earlier in this chapter for burden. Each variable was regressed on husbands’ depression scores. Significant variables were length of time providing care and percentage of care giving responsibilities. When these were regressed on depression with the significant demographic variables entered first as moderator variables, results indicated that correlation coefficients for the cluster variables were not statistically significant. Thus none of the cluster variables made a unique contribution to depression over and above the contribution made by the demographic variables.
Cluster Three Variables: Husbands’ Perceptions of Their Role

Cluster Three variables consisted of five variables which described husbands’ perceptions of their role and these were identified earlier in the chapter. Cluster variables were regressed on husbands’ depression scores. Findings indicated that care giving perceived as a ‘job’ and care giving seen as important were significantly correlated with depression, however, when the significant demographic variables entered the regression equation as moderator variables, care giving seen as being important and husbands’ religion left the model and care giving perceived as a ‘job’ and wives’ age remained in the new model.

Table 7.17

Multiple Regression Analysis with Husbands’ Perceptions of their Role

Regressed on Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted $^2$</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wives’ age</td>
<td>-.212</td>
<td>-1.798</td>
<td>.077</td>
<td>.031</td>
<td>1.000</td>
<td>22.348</td>
</tr>
<tr>
<td>Care giving perceived as a ‘job’</td>
<td>.141</td>
<td>1.161</td>
<td>.250</td>
<td>.036</td>
<td>1.070</td>
<td>28.330</td>
</tr>
</tbody>
</table>

From Table 7.17 it is evident that care giving perceived as a ‘job’ accounted for a small amount of the variance of depression (0.5%). As this variable was
positively correlated with depression the more husbands’ perceived care giving like a ‘job’ the greater their level of depression.

Cluster Four: Effects of Care giving on Husbands

There were five variables in Cluster Four and these were described earlier in the chapter as effects of care giving on husbands. When the cluster variables entered the regression equation, changes in husbands’ emotional health status, changes in feelings towards wife, and changes in husbands’ physical health status were found to be significantly correlated with depression.

Table 7.18

Multiple Regression Analysis with Effects of Care giving
Regressed on Husbands’ Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in husbands’ emotional health status</td>
<td>.566</td>
<td>5.353</td>
<td>.000</td>
<td>.298</td>
<td>1.000</td>
<td>1.000</td>
</tr>
<tr>
<td>Husbands’ religion</td>
<td>.221</td>
<td>2.188</td>
<td>.032</td>
<td>.388</td>
<td>1.001</td>
<td>6.236</td>
</tr>
</tbody>
</table>

As Table 7.18 demonstrates, when the demographic variables were entered into the regression equation as moderator variables, changes in husbands’ emotional
health status remained in the new model along with husbands’ religion but the
other variables left the model. The unique contribution of changes in husbands’
emotional health status was 29.8% of the variance of depression. Emotional
health status was positively correlated with depression indicating that as greater
changes in husbands’ emotional status associated with care giving occurred there
was a corresponding increase in husbands’ level of depression.

Cluster Five Variables: Effects of Care giving on Husbands’ Depression

Earlier in this chapter it was identified that Cluster Five consisted of nine
variables. Each was regressed on husbands’ depression scores. When the cluster
variables for effects of care giving on husbands were regressed on husbands’
depression scores, avoidant evasive coping strategies, regressive coping strategies,
affective personality traits, problem solving coping strategies and previous care
giving experiences were found to be significantly correlated with husbands’
depression scores. When the demographic variables were entered as moderator
variables, avoidant-evasive coping strategies, affective personality traits and
regressive coping strategies remained in the new model and the other variables
left the model.
Table 7.19

Multiple Regression Analysis with Role of Care giver
Regressed on Husbands’ Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative Adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive strategies</td>
<td>.596</td>
<td>5.932</td>
<td>.000</td>
<td>.345</td>
<td>1.000</td>
<td>7.392</td>
</tr>
<tr>
<td>Affective personality traits</td>
<td>-.256</td>
<td>-2.649</td>
<td>.010</td>
<td>.401</td>
<td>1.013</td>
<td>14.457</td>
</tr>
</tbody>
</table>

As Table 7.19 demonstrates, the unique contribution of avoidant-evasive coping strategies was 34.5% of the variance of depression and affective personality traits contributed a further 5.6%. As avoidant-evasive coping strategies was positively correlated with depression, husbands who used more avoidant-evasive coping strategies experienced more depression. Affective personality traits was negatively correlated with depression and husbands, therefore, with fewer affective personality traits were more likely to experience higher depression levels.
Cluster Six Variables: Supports: Relative and Friends and Religious Beliefs & Practices

Cluster Six comprised five variables as identified earlier in Chapters Four and in this chapter. When these were regressed on husbands’ depression scores ease of contact with relatives and friends, specific person to share with, number of relatives and friends providing support and religious beliefs and practices were significantly correlated with husbands’ depression scores. These variables were then regressed on depression along with the significant demographic variables which were entered first into the equation as moderator variables.

Table 7.20

Multiple Regression Analysis with Supports: Relatives and Friends and Religious Beliefs and Practices Regressed on Husbands’ Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P</th>
<th>Cumulative adjusted $R^2$</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease of contact with relatives and friends</td>
<td>-.304</td>
<td>-2.550</td>
<td>.013</td>
<td>.078</td>
<td>1.000</td>
<td>4.845</td>
</tr>
<tr>
<td>Wives’ age</td>
<td>-.259</td>
<td>-2.226</td>
<td>.030</td>
<td>.132</td>
<td>1.015</td>
<td>28.577</td>
</tr>
</tbody>
</table>

When the moderator variables entered the regression equation, ease of contact with relatives and friends remained in the model, and the other significant
variables and husbands’ religious affiliation left the model. From Table 7.20, we can see that ease of contact with relatives and friends accounted for 7.8% of the variance of depression and as this variable was negatively correlated with depression, as ease of contact with others decreased, husbands’ depression levels increased.

Cluster Seven Variables: Supports: Support Group Attendance

There were six variables in Cluster Seven related to husbands’ experiences with ADARDS’s support groups. Cluster variables were regressed on depression and from this analysis, number of relatives attending support groups and number of groups husbands attended were found to be significantly correlated with depression. When the significant demographic variables were entered into the regression equation with the significant cluster variables, none of the cluster variables remained in the equation, indicating that no cluster variables made a unique contribution to depression over and above that of the demographic variables.

Cluster Eight Variables: Characteristics of Wives’ Condition

Cluster Eight comprised five variables, described earlier in the chapter, that were regressed on husbands’ depression scores. From the analysis, wives’ problem behaviours was found to be significantly correlated with depression. When the
demographic variables entered as moderator variables, husbands’ religion and wives’ age remained in the new model and wives’ problem behaviours left the model indicating that the significant variables did not make a unique contribution to depression over and above the contribution of the demographic variables.

7.7 Significant and Non-Significant Variables from all Clusters

The relative contribution of the significant cluster variables from each of the clusters was regressed on depression so as to identify each variable’s unique contribution to the dependent variable. Wives’ age and husbands’ religion were entered into the regression equation first.
Table 7.21

Contribution of Significant Variables Regressed on Depression

<table>
<thead>
<tr>
<th>Model Number</th>
<th>Predictive Models of Depression</th>
<th>Cumulative Adjusted R²</th>
<th>Cumulative %age of Variance of Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Avoidant-evasive coping strategies</td>
<td>.345</td>
<td>34.5%</td>
</tr>
<tr>
<td>2</td>
<td>Changes in emotional status</td>
<td>.444</td>
<td>9.9%</td>
</tr>
<tr>
<td>3</td>
<td>Affective personality traits</td>
<td>.486</td>
<td>4.2%</td>
</tr>
<tr>
<td>4</td>
<td>Ease of contract with relative &amp; friends</td>
<td>.522</td>
<td>3.6%</td>
</tr>
<tr>
<td>5</td>
<td>Wives’ age</td>
<td>.529</td>
<td>.7%</td>
</tr>
<tr>
<td>6</td>
<td>Husbands’ religion</td>
<td>.534</td>
<td>.5%</td>
</tr>
<tr>
<td>7</td>
<td>Care giving perceived as a ‘job’</td>
<td>.539</td>
<td>.5%</td>
</tr>
</tbody>
</table>

From Table 7.21 four predictive models of depression were identified. In Model One, avoidant-evasive coping strategies contributed 34.5% of the variance of depression. In addition, models 2, 3, and 4. contributed a further 17.7%.

To ensure that no significant variables were missed from the analyses all non-significant variables from the eight clusters were regressed on depression. The analysis indicated that no significant variables were missed.
Consistent with the process that was employed to examine the interaction effects of various variables on burden described earlier in the chapter for burden, the researcher also examined the interaction effects of variables on depression. The results of this will be described next.

7. 8 Interaction Effects of Independent Variables with Depression

There were no studies from the literature review that had examined the interaction effects of various independent variables with the measures of carers’ burden and depression. As it was not possible to examine all interaction effects of the variables of interest, the researcher felt that it was a reasonable approach to examine the interaction of the first two predictive models: (1) avoidant-evasive coping strategies and (2) changes in emotional health status, with other cluster variables that the researcher hypothesized might be significantly correlated with depression when combined with each of the significant variables. Following the same approach identified in Section 7.5 this decision reflected a theoretical selection of variables to be included in the analysis. Although various possible significant correlations were noted, the researcher decided to report only those correlations that contributed over 20% of the variance of depression. The same approach was taken in relation to reporting interaction effects of selected variables with burden.
In this section avoidant-evasive coping strategies was combined with variables from Clusters Three, Four, Five and Eight to examine if there were any interaction effects when the selected cluster variables and avoidant-evasive coping strategies were regressed on depression. It was hypothesised that (1) where husbands were utilising more avoidant-evasive coping strategies and at the same time experiencing changes in emotional health status related to care giving, (2) perceived that care giving was like a job, and (3) were caring for wives whose illness was increasing in severity, would experience more depression. These hypotheses were then tested.

Firstly, avoidant-evasive coping strategies was regressed on depression in combination with changes in emotional health status related to care giving (Table 7.22). As we can observe from the table, avoidant-evasive coping strategies in combination with changes in emotional health status accounted for 39.4% of the variance of depression. As these variables were positively correlated with depression, husbands who used more avoidant-evasive strategies and at the same time were experiencing increasing changes in their emotional status experienced more depression.
Table 7.22

Interactive Effects of Avoidant-Evasive Coping Strategies with Changes in Emotional Health Status Related to Care giving Regressed on Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive coping strategies with change in emotional health status related to care giving</td>
<td>.635</td>
<td>6.826</td>
<td>.000</td>
<td>.394</td>
<td>1.000</td>
<td>7.717</td>
</tr>
<tr>
<td>Change in emotional health status related to care giving</td>
<td>.294</td>
<td>5.492</td>
<td>.121</td>
<td>.021</td>
<td>1.000</td>
<td>4.267</td>
</tr>
</tbody>
</table>

Secondly, the interaction effects of avoidant-evasive coping strategies combined with extent to which care giving has affected relationship and regressed on depressed, was also examined (see Table 7.23).
## Table 7.23

**Interactive Effects of Avoidant-Evasive Coping Strategies with Extent to which Care giving has Affected Relationship with Spouse Regressed on Depression**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive coping strategies with extent to which care giving has affected relationship with spouse</td>
<td>.614</td>
<td>6.470</td>
<td>.000</td>
<td>.369</td>
<td>1.000</td>
<td>7.725</td>
</tr>
<tr>
<td>Extent to which care giving has affected relationship with spouse</td>
<td>.253</td>
<td>2.169</td>
<td>.034</td>
<td>.050</td>
<td>1.000</td>
<td>3.544</td>
</tr>
</tbody>
</table>

From the table, we can observe that avoidant-evasive coping strategies combined with extent to which care giving had affected the relationship with spouses, accounted for 36.9% of the variance of depression. As the variables were positively correlated with depression, husbands using more avoidant-evasive coping strategies and experiencing increasing changes in their relationship with their wives experienced more depression.
Thirdly, avoidant-evasive coping strategies was combined with care giving perceived to be like a ‘job’ (a Cluster Three variable) and regressed on depression (Table 7.24).

From the table the combined variables accounted for 33.3% of the variance of depression and as the combined variables were positively correlated with depression, therefore, husbands who used more avoidant-evasive coping strategies and who increasingly perceived care giving perceived as a ‘job’ experienced more depression.

Table 7.24

Interactive Effects of Avoidant-Evasive Coping Strategies with Care giving Perceived as a ‘job’ Regressed on Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive coping strategies with care giving perceived as a ‘job’</td>
<td>.585</td>
<td>5.995</td>
<td>.000</td>
<td>.333</td>
<td>1.00</td>
<td>7.7741</td>
</tr>
<tr>
<td>Care giving perceived as a ‘job’</td>
<td>.186</td>
<td>1.572</td>
<td>.121</td>
<td>.021</td>
<td>1.00</td>
<td>4.122</td>
</tr>
</tbody>
</table>

Avoidant-evasive coping strategies was combined with care giving like a job and regressed on depression. From Table 7.25 we can observe that the combined variables accounted for 31.4% of the variance of depression.
Interactive Effects of Avoidant-Evasive Coping Strategies with Important to be Efficient and Organised Regressed on Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive coping strategies with important to be efficient and organised</td>
<td>.569</td>
<td>5.754</td>
<td>.000</td>
<td>.314</td>
<td>1.000</td>
<td>8.594</td>
</tr>
<tr>
<td>Important to be efficient and organised</td>
<td>-.034</td>
<td>-.282</td>
<td>.779</td>
<td>-.013</td>
<td>1.000</td>
<td>9.597</td>
</tr>
</tbody>
</table>

As the combined variables were positively correlated with depression, husbands who used more avoidant-evasive coping strategies and believed that it was important to be efficient and organised experienced more depression.

Finally, the interaction of avoidant-evasive coping strategies combined with severity of illness (a Cluster Eight variable) and regressed on depression was also examined (Table 7.26).
Table 7.26

Interactive Effects of Avoidant-Evasive Coping Strategies with Severity of Illness Regressed on Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative adjusted R^2</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant-evasive coping strategies with severity of illness</td>
<td>.493</td>
<td>4.706</td>
<td>.000</td>
<td>.232</td>
<td>1.000</td>
<td>10.642</td>
</tr>
<tr>
<td>Severity of illness</td>
<td>.035</td>
<td>.770</td>
<td>.293</td>
<td>.0139</td>
<td>1.000</td>
<td>9.466</td>
</tr>
</tbody>
</table>

From the table avoidant-evasive coping strategies combined with severity of illness accounted for 23.2% of the variance of depression. As the combined variables were positively correlated with depression, husbands who used more avoidant-evasive coping strategies and whose wives’ illness was increasing in severity, experienced more depression.

(2) Changes in Emotional Health Status

Changes in emotional health status was combined with several variables (from Cluster Five, an item from the Barriers to Care giving Index (Kaye & Applegate, 1990a.), and the Zarit Burden Scale) (Zarit et al., 1986) to examine if there were any interaction effects when these variables were regressed on depression. It was
hypothesised that changes in emotional health status combined with husbands’ burden (as measured by Zarit Burden Scale) (Zarit et al., 1986) and general stress (a non-cluster variable from Barriers to Care giving Index) (Kaye & Applegate, 1990a.) would result in more depression.

Firstly, the variable measuring changes in emotional health status was combined with husbands’ depression score. These variables were found to be significantly correlated with depression and accounted for 23.5% of the variance of depression. As these variables were positively correlated with depression, husbands who were experiencing changes in their emotional status and who were at the same time experiencing higher burden levels experienced more depression (see Table 7.27).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in emotional health status with husbands’ burden scores</td>
<td>.496</td>
<td>4.739</td>
<td>.000</td>
<td>.235</td>
<td>1.000</td>
<td>7.933</td>
</tr>
<tr>
<td>Husbands’ burden scores</td>
<td>.473</td>
<td>4.457</td>
<td>.000</td>
<td>.212</td>
<td>1.000</td>
<td>7.928</td>
</tr>
</tbody>
</table>
Secondly, the interaction effects of changes in emotional health status and general stress associated with care giving (a non-cluster variable from Barriers to Care giving Index) (Kaye & Applegate, 1990a.) was regressed on depression.

Table 7.28

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>T</th>
<th>P&lt;</th>
<th>Cumulative adjusted R²</th>
<th>VIF</th>
<th>Condition Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in emotional health status and general stress associated with care giving</td>
<td>.477</td>
<td>4.503</td>
<td>.000</td>
<td>.216</td>
<td>1.000</td>
<td>6.067</td>
</tr>
<tr>
<td>General stress associated with care giving</td>
<td>.281</td>
<td>2.435</td>
<td>.017</td>
<td>.066</td>
<td>1.000</td>
<td>6.635</td>
</tr>
</tbody>
</table>

From Table 7.28 we can observe that changes in emotional health status combined with general stress associated with care giving were significantly correlated with depression and accounted for 21.6% of the variance. As the variables were positively correlated with depression, husbands, who experienced changes in their
emotional health status and whose general stress associated with care giving also increased, experienced more depression.

To summarise, when avoidant-evasive coping strategies was combined with various theoretically selected variables, changes in carers’ emotional health status related to care giving, extent to which care giving has affected relationship with spouse, care giving perceived as a job, important for carer to be efficient and organised and severity of wives’ illness were the best predictors of carer depression. Following a similar procedure, when changes in carers’ emotional heath status related to care giving was combined with selected variables, husbands’ burden scores and general stress related to care giving were the best predictors.

7.9 Conclusions: Husbands’ Sense of Burden and Level of Depression and Interaction Effects of Independent Variables on Burden and Depression

Findings in this chapter indicated that a large number (80%) of husbands reported experiencing some level of burden associated with care giving as measured by the Zarit Burden Scale (Zarit et al., 1986). This finding is consistent with the findings from stage one of this study and those of other studies of family caregivers’ experiences. Significantly, 22% of the group reported feeling burdened quite frequently to nearly always. Findings in this section also indicated that 40% of husbands were experiencing some degree of depression with 14% experiencing
high levels of depression.

In addition, this section also examined those cluster variables that were associated with husbands’ burden and depression. When all the significant variables from each of the clusters were entered into the regression equation, care giving perceived as a job, effects of care giving on relationship, and avoidant-evasive coping strategies contributed over 50% of the variance of burden. Additionally, the variable avoidance-evasive coping strategies was found to make the greatest contribution to the variance of depression and changes in husbands’ emotional health status contributed an additional 9.9%.

From an examination of the interaction effects of independent variables with the dependent variables, three cluster variables were found to be significantly correlated with both burden and depression. These were avoidant-evasive coping strategies, affective personality traits and changes in husbands’ emotional health status (see Table 7.29).
Table 7.29

Cumulative Percentage of Significant Variables
for Burden and Depression

<table>
<thead>
<tr>
<th>Variables</th>
<th>Cumulative Percentage of Significant Variables</th>
<th>Regressed on Burden and Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Burden</td>
</tr>
<tr>
<td>Avoidance-evasive coping strategies</td>
<td>13.0%</td>
<td>34.5%</td>
</tr>
<tr>
<td>Affective personality traits</td>
<td>4.2%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Changes in emotional health status</td>
<td>0.4%</td>
<td>9.9%</td>
</tr>
</tbody>
</table>

From the table it is evident that each of the three cluster variables contributed unequal amounts to the variance of both burden and depression. Of the three variables, avoidant-evasive coping strategies made a higher contribution to the variance of both burden and depression than the other two variables but contributed a much higher proportion of the variance to depression rather than to burden. The variable, affective personality traits, made an equal contribution to the variance of both burden and depression and changes in husbands’ emotional health status contributed more to the variance of depression than to burden.
7.9.1 Significant Demographic Variables for Husbands’ Burden and Depression

Wives’ age was identified as a significant variable for both husbands’ burden and depression and accounted for 4.6% of the variance of both burden and depression (Tables 7.2 and 7.16). However, husbands’ main source of income was significantly correlated with burden but not depression and husbands’ religious affiliation with depression and not burden.

7.10 Conclusions

Findings in this chapter indicated that husbands experienced both burden and depression associated with care giving. However, burden and depression are not unrelated phenomena, as study findings might suggest, but are interrelated. For example, it can be hypothesised that feelings of burden after a while may have made some husbands quite depressed, moreover, feeling depressed could lead to a greater sense of burden.

While significant variables from clusters were identified for most clusters, not all cluster variables reached significance when regressed on burden and depression. Identification of the significant cluster variables allowed the researcher to develop an understanding of specific factors that might place husbands ‘at risk’ of developing significant physical and mental health problems. A particular feature
of the present study was the identification of interaction effects of variables when combined on burden and depression. The best predictive model of burden was

- care giving perceived as a ‘job’ combined with care giving has affected relationship with spouse

The best predictive model of depression was

- avoidant-evasive coping strategies combined with changes in emotional health status related to care giving.

Reflecting on research question 1 identified in Chapter Four which aimed to identify those husband and wives’ characteristics that had the most impact on husbands’ a) sense of burden, and b) level of depression, from the data, the best predictive models of caregiver burden were care giving seen as a ‘job’, effects of care giving on relationship, and avoidant-evasive coping strategies. Taken together, these accounted for over 50% of the variance of burden. Husbands, therefore, were experiencing a greater sense of burden where they perceived care giving to be seen as a ‘job’, where care giving resulted in negative impacts on the husband-wife relationship and where they used more avoidant-evasive strategies to cope with care giving experiences.

The best predictive models of depression were avoidant-evasive coping strategies, and changes in husbands’ emotional health status, which together accounted for 44.4% of the variance of depression. Husbands, therefore, were more depressed where they used more avoidant-evasive strategies to cope with care giving and at
the same time experienced changes in their emotional health related to care giving.
CHAPTER EIGHT
DISCUSSION AND CONCLUSION

Introduction

This chapter presents a summary and discussion of the findings from stages one and two of the study. Additionally, the chapter includes an appraisal of the research process utilised in this study and an examination of the implications arising from the study. Finally, the researcher notes possible limitations of the study design and highlights future directions for research in relation to husband care giving experiences in dementia.

8.1 Overview of the Study

Because there were few published studies of husbands’ experiences associated with providing care for wives with dementia, the researcher designed a two-stage project incorporating distinctive investigative methodologies. In stage one, a qualitative paradigm guided one-on-one interviews with sixteen care giver husbands to examine their experiences with wives over time. In stage two, questionnaire items that formed a comprehensive survey were identified from multiple sources: A representative sample of husbands participated by completing the questionnaire. Research processes and discussion of findings from each stage are elaborated below.
8.2 Stage One Results

Analysis of the data derived from interviews with sixteen care giver husbands allowed the identification of themes and sub-themes. Husbands’ interpretations of what care giving meant to them reflected the Past, the Present, and the Future. In relation to the Past, the main theme was Deciding to Care. Burden emerged as the major concern in the model of the Present, as wives’ condition continued to deteriorate and they were required to provide increasing amounts of supervision, and this impacted on opportunities to meet their own basic needs. The main theme for husbands in relation to future care giving experiences was Fear of the Future and Doubts about their ability to continue to care.

Many of the study informants were experiencing a sense of burden and some may have become depressed. It is possible that each of these contributed to a self-perpetuating spiral, that is, feeling burdened may have made husbands depressed and being depressed may have increased husbands’ sense of burden.

This section provides a summary of the characteristics which typified the couples where the wife was suffering a dementing illness. Descriptive results in stage one of the study indicated that husbands and wives were of a similar age and had been married for many years. Husbands had been working for most of their adult lives and wives had largely remained at home. A pension was the main source of income for one quarter of husbands interviewed.
All wives had been diagnosed with dementia. Husbands had noticed that there had been significant changes in their wives’ behaviour. Husbands reported that some behavioural changes had been present to a greater or lesser extent prior to diagnosis and that they had been providing varying levels of care before the diagnosis was made. Memory loss was the most common change in behaviour reported by husbands but changes in emotions, behaviour and orientation were identified as well.

8. 2. 1 Carers’ Reactions to the Diagnosis of Dementia

Reactions to changes in wives’ behaviour, relating to the onset and development of dementia, varied from husband to husband with some suspecting that their wives had developed a dementing illness, and others recognising that something was significantly wrong, without knowing what specifically. Commonly, the response of husbands to a confirmed diagnosis of dementia was intensely emotional. For some, the diagnosis affirmed their own suspicions about what was happening. Most husbands had come to terms with the diagnosis although the extent of their acceptance varied, with a few expressing hope for a cure. Some wives recognised that there was something wrong without realizing or acknowledging the significance of the illness in terms of its effects on them and related prognosis.

At the time of interview, there had been an increase in the number of problem
behaviours being experienced and earlier problem behaviours had become more pronounced. Specifically, wives were experiencing changes in behaviour, orientation, communication, problems with activities of daily living, interpreting the environment, cognitive, emotional and physical problems. Wandering was a common behavioural problem and memory loss continued to be a significant, prominent and increasing problem. Wives’ physical health problems were not necessarily directly caused by the dementing process but the dementing process could have made wives more susceptible to physical health problems. Additionally, wives and husbands were getting older and were, therefore, more susceptible to the development of physical health problems.

8.2.2 The Challenges of Care giving

Husbands’ descriptions of their care giving indicated that they were experiencing strong emotional reactions to the role. Their psychological distress was found to be related to their wives’ problem behaviours, the nature of the work of caring, a sense of isolation, choice restrictions, relationship changes and their own physical health problems. Frustration was a commonly expressed reaction to care giving experiences. Frustration was associated with wives’ problem behaviours and the impact that these had on husbands. Many husbands reported that their wives no longer recognised them as being their spouse and this was a distressing experience. Husbands also reported that care giving experiences resulted in interrupted sleep, extra and unpleasant work and around the clock supervision.
Several husbands expressed that they were concerned about what the future held. Most husbands still carried out their normal duties and to this they had added their wives’ duties around the house as well as their day to day care. Care giving limited the day to day, short-term and long-term plans that husbands could make.

Care giving affected husbands socially, physically, emotionally, psychologically, relationally, occupationnally and prevented them from pursuing hobbies and other activities. It restricted husbands’ social activities and relationships with others. Physically, many husbands were tired through lack of sleep and exhausted through providing around the clock care giving activities. Care giving commonly resulted in a sense of isolation and feelings of loneliness. For many husbands communication with wives had become significantly affected and for most communication was difficult. Several husbands reported that sexual relationships were no longer possible.

Several husbands reported that moving into the care giving role hadn’t been difficult. Some explained this phenomenon in terms of earlier care giving experiences and family socialisation and training. For others, we might speculate that because they were retired they were able to devote time and effort to the care giving role. Another hypothesis might be that care giving provided meaning and purpose in retirement and a substitute for previous occupational responsibilities. However, some husbands who indicated that care giving wasn’t difficult, elsewhere in the interview, reported that it had caused significant changes in their
usual roles and other problems for them as well. The explanation for this seeming contradiction could be that some husbands were unable to acknowledge the physical, emotional and psychological problems that they were experiencing related to care giving and may have needed professional assistance to do this and work through the ways these experiences were affecting them. This interpretation of the data appears to be consistent with findings by Miller (1987) and Mathew et al. (1990) who reported that male carers had more difficulty acknowledging their stress level.

8. 2. 3 Care giver Motivation

Husbands’ motives for providing care varied. Commonly, husbands reported that they took on the care giving role because of love for their wives, their marriage vows and as a tangible way to repay their wives for all that they had done for them. Similar findings were reported by Pruchno & Potashnik (1989), Harris (1993, 1995), Parsons (1997) and in the ABS report of 2003 as described by the writer in Chapter Two. Additionally, in the present study husbands highlighted that it was better for one person to provide care than many carers, for example, where a wife is placed into an institutional setting and is looked after by many formal carers, including nurses. Moreover, other husbands believed that wives would function better in an environment that they were more familiar with (their own home). Arguably, these motives kept them going in the face of having to
manage wives’ problem behaviours and having to carry out various care giving and other responsibilities.

8. 2. 4 Care giver Activities

Husbands estimated that they provided between 50% and 100% of all care giving effort with a high proportion (94%) reporting that they provided between 80% and 100%. This finding is at odds with the finding of an early study by Finch & Groves (1983) that male carers devoted low levels of time to care giving tasks. The explanation could be that their study didn’t comprise high numbers of older husband carers. In the present study, husbands were providing a range of care giving activities and the majority of husbands clearly were assuming primary responsibility for their wives’ care including making decisions about what services would or would not be used. The finding is consistent with that reported by Barusch & Spaid (1989) who found that male carers assumed responsibility for a wide range of care giving activities.

For some husbands, structure, routine and being organised helped them to cope with care giving experiences and responsibilities. This finding is similar to that of Harris (1993, 1995) who reported that one of the findings identified by male carers in his study was the importance of a structured routine in combination with respite care. However, whilst respite care was utilised by husbands in the present study and identified as a specific present and future need, day care was utilised
more. This finding is at odds with that of Archer & McLean’s (1993) who highlighted male carers’ need for respite care. It could be that wives in their study were at a more advanced stage of their illness and, therefore, respite was a high priority.

Husbands also assumed responsibility for shopping, cooking, cleaning, banking, correspondence, washing and ironing. They also were responsible for, or arranged, home care and maintenance. This finding is consistent with that of Jansson et al. (2001) who reported that carers engaged in demanding and time consuming care activities. Husbands in the present study provided assistance with wives’ toileting, washing and showering needs. Although some husbands in the present study found toileting distasteful this attitude did not prevent them from carrying it out, a finding inconsistent with Gregory, Peters & Cameron’s (1990) finding that male carers were uncomfortable in attending to wives’ personal hygiene needs.

From the data, husbands identified various ways in which they managed their care giving experiences. Some husbands, for example, looked back and were grateful for the good times together, a few related that they didn’t look too far ahead. Other husbands reported that they realised and accepted that they could only do so much for their wives. Time out was found to be a helpful strategy as were relaxation classes and support group lectures to assist husbands in their care giving role. For others religious beliefs and practices provided beneficial support.
8. 2. 5 Shaping and Sharing the Care giving Role

Various strategies were employed by husbands to manage wives’ problem behaviours. These included doing things together, doing things wives liked to do, keeping wives occupied and introducing environmental changes to make care giving easier thus reducing perceived threats to wives’ safety. Similar findings were also highlighted by Quayhagen & Quayhagen (1988) who reported that carers used cognitive stimulation to manage wives’ behaviour. Unfortunately, study findings showed that this approach led to a decreased sense of wellbeing as cognitive stimulation was eventually resisted by wives. In the present study some husbands also used vitamins in the belief that they would keep their wives physically well and might even assist their cognitive functioning.

Support for husbands was provided informally and formally. Informal supports comprised family members, friends, neighbours and to a lesser extent the general public. In some instances, help from neighbours was not always appreciated by wives as they had become suspicious about who they were and what they wanted. Almberg et al. (1998) found that there was sometimes conflict between family members while in the present study conflict between family members was not reported, some husbands shared that family members did not always appreciate all that was involved in care giving and sometimes felt that their fathers (the husbands in the study) were making too many decisions on behalf of their
mothers. One interpretation here is that family members did not always have a full understanding of the significance of their mothers’ illness.

Family members provided varying levels of support. Support was provided mainly by adult children, the majority of whom lived outside of the household. However, family support was not always available as many family members lived geographically distant from their parents. This finding is consistent with that of Parsons (1997), however, Parsons found that where they were available they were reported to be highly beneficial - this was not always the case in the present study.

The present study found that care giving restricted spending time with family members and friends. A similar outcome, associated with care giving, was also reported by Mittelman (2003). There was also some evidence that adult daughters in particular provided support for their fathers although the ways in which this they provided help was not specifically investigated. Mittelman (2003) also reported that daughters were more likely to provide assistance for parental carers. However, it is unclear if this resulted from pressure from their fathers to provide help, or that daughters were more likely to perceive their fathers’ need for assistance. These finding are at odds with those of Brodaty & Hadzi-Pavlovic (1990) who related that few family members provided help with care giving and that care giving had an isolating effect.
Husbands utilised a range of external support services. These included respite care, day care, home care, support groups, hospital services, community nurses and meals on wheels. Day care was the most commonly used service. Respite care provided temporary relief from care giving and several husbands used home care services. Quayhagen & Quayhagen (1988) also reported that respite services were associated with a sense of carer wellbeing. Few husbands in the present study used meals on wheels. More than half of the sample attended support groups associated with the Alzheimer’s Association. Support groups provided information about dementia, allowed and encouraged discussion of experiences provided mutual support and facilitated information sharing. Elsewhere, Archer & McLean (1993) highlighted that support groups should be sensitive to male carers’ needs. In the present study it was evident that this was not always so.

Community nurses provided a range of services including respite so that the carer could do others things, information about wives’ health problems and management problems, information about the Carers’ Pension as well carrying out ongoing assessment of the carer and care-recipient.

During interviews, husbands identified that the following needs were not being currently met. These were someone to ‘sit’ with wives while they attended to other responsibilities, night care for wives, time out to visit friends, weekend respite services, more family involvement, home care, assistance to bath wives, and assistance with lawn and home maintenance, remained unmet.
From the totality of the findings from this qualitatively driven study one and with the assistance of professional and collegial sources, a questionnaire was developed, and standardised measures identified, in order to examine further the care giving experiences of husbands who were the sole and primary carers of their wives with dementia.

8.3 Stage Two Results

Several research questions directed stage two of the study and these were reported in Chapter Four. In the remainder of this chapter, results of the analysis of the data for stage two will be presented under each research question. In addition, any other relevant findings from stage one will be added to provide a more complete picture of husbands’ care giving experiences.

8.3.1 Research Question 1: Which Husbands’ and Wives’ Characteristics are the Best Predictors of Husbands’ Burden and Depression?

In the following section husbands’ and wives’ demographic predictor variables will be identified and discussed. Characteristics also included effects of husbands’ upbringing, previous care giving and work experiences, religious beliefs and practices, personality traits and coping strategies.
Wives’ current condition comprised the severity of their dementing illness state and specific behavioural problems related to their illness.

Findings from stage one of the study, suggested that care giving for husbands produced a sense of burden. For example, when asked what it had been like to provide care for their wives, husbands responded with a range of emotive words to describe the experience and its effects on them as described in Chapter Five. Husbands’ sense of burden was related to wives’ behaviour associated with their dementing illness and the effects care giving experiences were having on them, including demands for increasing supervision, which resulted in an inability to meet their own needs.

A descriptive analysis of the data for the Zarit Burden Scale (Zarit et al., 1986) in stage two of the study yielded a high proportion of husbands (79%) who reported experiencing some level of burden and just over 20% of these who were experiencing a sense of burden ‘Quite frequently’ to ‘Nearly always’. To identify those factors that contributed to husbands’ sense of burden, each of the variables in the eight variable clusters that were created by the researcher was regressed on husbands’ burden scores. Table 8.1 identifies all of the cluster variables that were found to be significantly correlated with husbands’ burden scores.
<table>
<thead>
<tr>
<th>Cluster Variables</th>
<th>Variables significantly correlated with burden</th>
<th>Contribution of the significant variables to the variance of burden</th>
<th>Type of Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>• Wives’ age</td>
<td>4.6%</td>
<td>Negative</td>
</tr>
<tr>
<td></td>
<td>• Husbands’ main source of Income</td>
<td>3.2%</td>
<td>Positive</td>
</tr>
<tr>
<td>Two</td>
<td>• Characteristics of care giver effort</td>
<td>- not significantly correlated with burden</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>• Care giving seen like a job</td>
<td>23.1%</td>
<td>Positive</td>
</tr>
<tr>
<td>Four</td>
<td>• Changes in emotional health</td>
<td>22.5%</td>
<td>Positive</td>
</tr>
<tr>
<td></td>
<td>• Effects of care giving on</td>
<td>11.8%</td>
<td>Positive</td>
</tr>
<tr>
<td></td>
<td>Relationship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Five</td>
<td>• Avoidant-evasive strategies</td>
<td>19.8%</td>
<td>Positive</td>
</tr>
<tr>
<td></td>
<td>• Affective personality traits</td>
<td>10.5%</td>
<td>Negative</td>
</tr>
<tr>
<td></td>
<td>• Problem solving strategies</td>
<td>8.3%</td>
<td>Negative</td>
</tr>
<tr>
<td>Six</td>
<td>• Cluster Supports: Relatives &amp; friends; religious beliefs &amp; practices – None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seven</td>
<td>• Supports: Support group</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• attendance – None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eight</td>
<td>• Problem behaviours</td>
<td>10.6%</td>
<td>Negative</td>
</tr>
</tbody>
</table>
When the significant variables from each of the clusters were entered into a regression equation, the results demonstrated that three regression models contributed over 50% to the variance of burden as follows: care giving perceived like a job (24.2%), effects of care giving on relationship contributed a further 13.1% and avoidant-evasive coping strategies an additional 13%. The remaining variables contributed less than 10%.

A distinctive feature of this study was that significant independent variables were regressed with other significant independent variables on husbands’ burden scores. Husbands experienced more burden:

1. where they perceived care giving was like a job and felt that the relationship with their wives had been affected by care giving;

2. where they perceived care giving was like a job and where their feelings towards their wives had changed;

3. as effects on the relationship increased and more personality changes occurred;

4. as effects on the relationship increased and husbands utilised more avoidant- evasive coping strategies;

5. as effects on the relationship increased and wives experienced changes in their personalities;

6. where they used more avoidant-evasive coping strategies and increasingly perceived care giving was like a job;
7. where effects of care giving and feelings towards relationship continued to deteriorate;

8. where they used more avoidant-evasive coping strategies and experienced continuing changes in their emotional well-being.

The findings from each stage of the present study that husbands experienced a sense of burden associated with care giving experiences and responsibilities, is consistent with findings of studies by various researchers including Carlson & Robertson (1993), Kaye & Applegate (1990b.), Mathew et al. (1990), Miller (1990), Kramer (1997); Kramer & Lambert (1999), and Kramer (2000).

8. 3. 1. 2 Husbands’ and Spouses’ Characteristics that Predicted Depression in Male Carers

As reported in Chapter Five, in stage one of the study, several husbands used various emotive words to describe their experience of care giving that indicated possible depression, including sad and saddened, feeling flat, getting upset, hurt, and of having suicidal thoughts. Sadness was associated with a sense of loss. Several husbands became weepy during their interview. One husband became so emotional that the interview had to be stopped until he became more composed. It was not clear from stage one of the study whether husbands were clinically depressed and if they were, what specific aspects of their experience this may
have been related to. From the data, husbands’ depression was associated with care giving responsibilities associated with their wives’ dementing behaviour.

In stage two of the study, descriptive analysis of the data from the Beck Depression Inventory (Beck et al., 1961) indicated that nearly 40% of the group of husbands were experiencing some level of depression and of these nearly 23% were depressed ‘Quite frequently’ or ‘Nearly always’, thus confirming the researcher’s impressions from stage one of the study that many husbands in addition to having a sense of burden, were also feeling depressed. This finding is consistent with that of Gallichio et al. (2002) who reported that both male and female spouses had higher depression scores than non-spouse carers.

At the beginning of stage two of the present study, the relationship between husbands’ depression and particular aspects of care giving was not clear. Once all of the cluster variables were regressed on depression, those most associated with depression were identified (Table 8.2).
Table 8.2

Significant Correlations: Cluster Variables with Depression

<table>
<thead>
<tr>
<th>Cluster variables</th>
<th>Variables significantly correlated with depression</th>
<th>Contribution of the significant variable to the variance of depression</th>
<th>Type of correlation</th>
</tr>
</thead>
</table>
| One               | • Husbands’ religious affiliation  
                    • Wives’ age                         | 5.8%
                    4.6%                                             | Positive  
                    Negative                                         |
| Two               | • Characteristics of care givers’ efforts – not significantly correlated with depression | | |
| Three             | • Care-giving seen like a job                    | 0.5%                                                 | Positive           |
| Four              | • Changes in husbands’ emotional status          | 29.8%                                               | Positive           |
| Five              | • Avoidant-evasive strategies  
                    • Affective traits                          | 34.5%  
                    5.6%                                             | Positive  
                    Negative                                         |
| Six               | • Ease of contact with relatives & friends       | 7.8%                                                 | Negative           |
| Seven             | • Supports: Support group  
                    • attendance - None                          | | |
| Eight             | • Characteristics of wives’ Condition - None     | | |
When all of the significant variables from each of the clusters were regressed on depression, four predictive regression models were identified. In model one, avoidant-evasive strategies contributed 34.5% of the variance of depression and changes in husbands’ emotional health status contributed 29.8%, affective personality traits and ease of contact with relatives and friends contributed an additional 13.4%. Husbands, therefore, who used more avoidant-evasive coping strategies, who experienced changes in their emotional health status associated with care giving, and who had difficulty contacting relatives and friends in relation to support needs associated with their care giving responsibilities, experienced more depression.

Interaction variables were also examined and regressed on depression. Husbands experienced more depression where they:

1. used more avoidant-evasive coping strategies and were experiencing increasing changes in their emotional status;
2. were using more avoidant-evasive coping strategies and experiencing more changes in their relationship with their wives;
3. used more avoidant-evasive coping strategies and perceived care giving to be like a job;
4. used more avoidant-evasive coping strategies and believed that it was important to be efficient and organized;
5. used more avoidant-evasive coping strategies and wives’ illness was increasing in severity;
6. were experiencing changes in emotional health status and experiencing more burden;
7. were experiencing changes in their emotional health status and whose general stress associated with care giving was increasing.

The following sections address the impact or otherwise of other husbands’ and wives’ characteristics on husbands’ burden and depression.

Effects of Upbringing, Previous Care giving Experiences and Previous Work experiences on Husbands' Burden and Depression

From stage one data there was a small group of husbands who reported that for them care giving had not been a difficult experience. Their explanation was that early upbringing experiences or experiences during the marriage, including the raising of children, had been helpful for their present role as carers. Several husbands stated that they had been encouraged by parents to cook, wash clothes, iron and sew on buttons. However, in stage two, the variable, effects of upbringing, was not found to be a significant predictor of burden or depression.
Effects of Prior Care giving Experiences on Husbands’ Burden and Depression

From stage one findings, several husbands stated that they had been encouraged by parents to cook, wash clothes, iron, and sew on buttons. In stage two of the study husbands were asked, *To what extent do you feel your upbringing has prepared you for the care-giving role?* (Questionnaire Item 34). From a descriptive analysis of the data from this questionnaire item, 27 husbands (38%) reported that it ‘Mostly’ or ‘Totally’ helped prepare them for the care giving role. When asked to elaborate on the ways in which previous care giving experiences had assisted in their present role, husbands identified having to assist with sick family members, having to care for self when others were not around, being brought up in a large family and having to help younger children.

In stage two, thirty (43%) husbands indicated that they had previous experiences providing care. Of these, a high proportion of husbands reported that their previous care giving experiences had assisted them with their present role. These included assisting others, other siblings where they came from a large family, those in need of help and providing assistance with their own children. When asked about the extent to which previous experiences had been helpful for their present role, a large proportion (85%) of husbands reported that the experiences had been helpful. In stage two of the present study, however, previous care giving experiences was not found to be significant predictor of burden or depression.
Effects of Previous Work Experiences on Husbands’ Burden and Depression

There were no data from stage one of the study that suggested that previous work experiences had been helpful or otherwise in relation to present care giving experiences. In stage two several questionnaire items were designed to investigate whether husbands perceived that previous work experiences (for example, Questionnaire item 45) assisted with their present role. Nearly 48% of husbands reported that previous work experiences helped with their present care giver role. Of these, 17% identified that previous work experiences helped ‘Mostly’ or ‘Totally’ with their present role. Interestingly, 21% of husbands reported that their present role was similar in many respects to the job that they used to do. Husbands who answered this item in the affirmative reported the following similarities: service to others; decision-making; supervising others; exercising care in relation to limited finances; doing the best one can. The concept of supervising others was also found by Miller (1987) to be a characteristic of husbands’ thinking in relation to care giving. Specifically, Miller reported that being in charge of others was seen by husbands as an extension of their authority figure role. Collins & Jones (1995) finding that male carers were more involved in managerial tasks may also highlight the effect of previous work experiences on males’ care giving experiences. Perhaps also this provided a familiar structure to the day in a situation that could be somewhat chaotic.

A high proportion (94%) of husbands reported that it was ‘Mostly’ or ‘Totally’
important to be organised and efficient on a day-to-day basis. Significantly, 69% of husbands in the study perceived that care giving was like a job. In addition, care giving perceived ‘like a job’ was found to be a significant predictor of burden, explaining 24.2% of the variance of burden but a much smaller proportion (0.5%) of the variance of depression. Conceivably, as their approach to care giving was based on a ‘worker’ model burden may become more of a problem as the care giving role progressed and wives’ behaviour became more problematic.

In addition to exploring the previous life of husbands in this study, other relevant aspects of their personal resources were extrapolated from the data.

**Effects of Religious Beliefs and Practices on Husbands’ Burden and Depression**

Religious beliefs and practices for many husbands in stage one of the study were important sources of carer support. In stage two, two thirds of the respondents to the item “Pray”, “Trust God” from the Jaloweic Coping Strategies Scale (Jaloweic et al., 1984), reported that they used this coping strategy “Almost always” or “Often”. Husbands’ responses to questionnaire item 5, What is your religion? in stage two, indicated that 55 husbands (77%) identified with a particular religion. It could be that husbands were trying to make sense of the illness and their present situation by developing a sense of purpose and meaning in the midst of chaos and loss and religious practices provided a focus for this way of thinking. This interpretation is also consistent with the conclusions reached by Borden & Berlin
(1990) in their study about the purpose of religious beliefs and practices in relation to care giving. This is not to suggest that male carers ‘became religious’ when they were faced with care giving rather their experiences of these phenomena intensified to assist them in their ordeal. When husbands’ religion was regressed on their burden and depression scores it was found that it accounted for 5.8% of the variance of depression but was not significantly correlated with burden. A possible explanation for this finding might be that initially their religious beliefs sustained them in relation to the development of their wives’ illness. Initially also, care giving would not have been such a burden. As time went by though and their sense of burden increased, it is possible that their religious beliefs and practices did not provide any answers to their difficult situation and for many this might have caused them to become somewhat depressed in relation to their situation. Alternatively, it is possible that religious beliefs and practices may have alleviated depression or even forestalled a deeper level of depression.

Effects of Husbands’ Personality Traits on Burden and Depression

There were no data from stage one of the study about the influence of husbands’ acquired or inherited personality traits on their sense of burden and depression. From stage two of the study it was found that affective personality traits contributed 4.2% of the variance of burden and depression. As affective traits was negatively correlated with burden and depression, husbands who scored low on
affective traits experienced more burden and depression. These findings are similar to those of Kaye & Applegate (1990b.) who found that those male carers who described themselves in affective terms experienced lower levels of burden.

Effects of Husbands’ Coping Strategies on Burden and Depression

Husbands in stage one of the study used a range of coping strategies in relation to their care giving experiences. In the present study husbands’ coping strategies included thinking about the good times together, accepting the present situation as things could be worse, not looking too far ahead, approaching difficulties with a positive frame of mind, and only doing what was possible to do. Moreover, finding relevant information was also seen as being helpful, as were attendance at relaxation classes and religious beliefs and practices. However, husbands were less able to maintain outside interests and activities as time went on. This was an unfortunate consequence, since being able to maintain outside interests had been found, in Archer & MacLean’s (1993) study, to assist male carers to cope better with care giving responsibilities.

In stage two, husbands’ coping strategies were examined using Jalowiec’s Coping Strategies Scale, since the researcher wanted to determine if particular types of coping strategies contributed to an increased sense of burden and depression. From the results of the analysis, avoidant-evasive coping was found to contribute 13% of the variance of burden and 34.5% of the variance of depression. As these
coping strategies were positively correlated with burden and depression, husbands who used more avoidant-evasive coping strategies experienced more burden but particularly more depression. This finding is similar to the results reported by Kramer (1997) who found that the use of emotion-focused strategies (including avoidant-evasive and regressive coping strategies) increased husband-carers’ sense of strain. However, problem-solving strategies made a smaller contribution (4.8%) to the variance of burden. As ‘problem-solving strategies’ was negatively correlated with burden, husbands who used these strategies less often experienced greater burden. It is not difficult to understand why husbands who utilised avoidant-evasive strategies more experienced more burden and depression, but it is unclear why the use of more problem-solving strategies was negatively correlated with burden and depression. A possible explanation here is that at first, problem-solving strategies were effective but eventually, with the progress of the disease and the development of more problem behaviours, they failed to provide solutions to the problems being experienced, an explanation also reported by Brown et al. (1995) in their study of family carers.

**Effect of Wives’ Condition on Husbands’ Emotions**

In stage one it was clear that problem behaviours identified as being present when a diagnosis was made had now become more pronounced and to these others been added. Problem behaviours included memory changes, suspiciousness, wandering, uncooperativeness, changes in orientation, cognitive impairment,
communication problems, repetitious and dangerous behaviours. Husbands used various emotive words to describe the way in which wives’ behaviour was affecting them as described in Chapter Five. For many husbands, their wives’ behaviour led to feelings of frustration. Frustration was related to wives’ memory loss, nuisance and non-cooperative behaviour, mistakes, wandering, following carer around and failure to pass on messages from others.

In stage two of the study wives’ behaviour was investigated further in relation to husbands’ experiences of burden and depression. Specifically, the Problem Behaviour Checklist (Zarit et al., 1980) was regressed on husbands’ burden and depression scores. However, findings indicated that the variable problem behaviours was not significantly correlated with husbands’ burden and depression. This is perhaps an unexpected finding. The explanation here could be that, even though problem behaviours had not become as significant at the time of interview, sufficient changes in behaviour had occurred to indicate to husbands that things were not quite right; and perhaps they had an understanding at some level that things would only get worse. Another possible explanation is that husbands were under-reporting symptoms as Miller (1987) proposed elsewhere. Over 60% of husbands in the present study reported that wives’ physical, mental and emotional health status affected the amount of care giving that they could provide.

Additional information was derived from a descriptive analysis of one of the items in the Barriers to Caregiving Index (Kaye & Applegate, 1990a.). Here, care
givers were asked about the extent to which their wives’ physical health status limited the amount of care that they could give them. From the findings, 45 husbands (63%) reported that it had ‘an effect’. Of these, 18 (25%) reported that it had a ‘profound’ effect. In addition, 49 (69%) husbands reported that the mental or emotional health of spouses influenced the amount of care that they could provide and 25 (35%) of these husbands reported that it had a ‘profound’ effect. Similarly, changes in wives’ personality associated with dementia was reported by just over 70% of husbands to limit the amount of their care giving. Of these, 23 husbands (32%) reported that it had a ‘profound’ effect.

Additional information derived from a descriptive analysis of the Clinical Dementia Rating Scale (Berg, 1988) indicated that wives were experiencing on average between ‘moderate’ and ‘severe’ memory loss; between ‘difficulty in orientation with time’ and ‘only knows who she is’; between ‘only doubtful or mild impairment’ and ‘severely impaired judgment and problem-solving’; between ‘only doubtful or mild impairment’ and ‘unable to function independently in relation to community affairs’; between ‘mild but definite impairment’ and ‘only simple chores preserved in relation to life at home and hobbies’; and in relation to personal care, ‘requires assistance in dressing, hygiene, keeping of personal effects’.

These findings are consistent with those of other researchers who identified that feelings of burden and stress were related to wives’ severely disturbed behaviour.
(Parsons, 1997; Gallichio et al., 2002), memory loss (Kramer, 1997), cognitive impairment (Parsons, 1997), destructive behaviour and emotional lability (Croog et al., 2001).

8. 3. 2  Research Question Two: To What Extent did Changes in Husbands’ (a) Physical and (b) Emotional Health Associated with Care giving Predict Husbands’ Burden and Depression?

In the following section each of these issues will be discussed.

8. 3. 2. 1  Physical Health Changes, Care giving, and Burden and Depression

In stage one of the study husbands described the physical effects associated with care giving and these included exhaustion, tiredness through lack of sleep and constant monitoring of their wives’ behaviour. In stage two of the study, there were several sources of information about the effects of care giving on husbands’ physical health. For example, Questionnaire Item 16 requested husbands to indicate the extent to which care giving had contributed to a change in their physical health status. Nearly 60% of husbands reported that there had been some changes in their physical health status associated with care giving. Of these, nearly 13% identified that physical changes were ‘Mostly’ or ‘Totally’ related to providing care. This finding is consistent with that reported by Pruchno & Potashnik, (1989) who found that male carers experienced high rates of physical
health problems and with Parsons (1997) who reported that providing care had caused carers’ health to deteriorate.

From the Barriers of Care-giving Index (Kaye & Applegate, 1990a.), twenty-five husbands (35%) reported that their general health limited the amount of care they were able to provide ‘To some extent’ and nine husbands (13%) reported that it limited it ‘Very much’. It is clear then, that for some husbands their own general health status may have limited the amount of care that they were able to provide. It is certainly possible that husbands’ physical health changes directly resulted from care giving experiences and responsibilities, but these could also have been associated with their own health problems perhaps unrelated to, or exacerbated by, care giving, as well as the effects of the ageing process on body systems, particularly in older carers.

In stage two, the variable ‘changes in physical health status’ was not significant when regressed on husbands’ burden or depression scores.

8. 3. 2. 2 Emotional Health Changes, Care giving, Burden and Depression

In stage one of the study husbands reported feeling lonely and isolated, and one husband expressed that he had experienced death wishes. Husbands also reported feeling angry, worried, frustrated, feeling mad and anxious, being fearful, flat and sad in relation to their present situation.
In stage two of the study, questionnaire item 17 asked husbands to indicate the extent to which changes in their emotional health status was associated with care giving. Just over 66% of husbands reported that there had been some changes in their emotional health status. Of these, over 25% indicated that these changes were ‘Mostly’ or ‘Totally’ associated with care giving. It is noteworthy that twice as many men reported changes in their emotional health compared to changes in physical health status, associated with care giving. This finding is consistent with that obtained by regressing changes in emotional status with husbands’ burden. From the regression analysis it was observed that changes in husbands’ emotional health status contributed a small proportion (.4%) of the variance of burden but more (9.9%) to the variance of depression. By way of interpretation it could be that those who had experienced a sense of burden earlier had gone on to be depressed about their situation. These are interesting findings as elsewhere (for example, Miller, 1987) reported that male carers were not able to discuss feelings about the role and may highlight that interviews, as used by Miller, may not always be able to facilitate a description of male’s emotional responses to care giving, whereas, the use of standardised scales may provide more information about this variable.

From stage one of the study, it was found that many wives no longer recognised their husband as their spouse. This caused husbands to react with feelings of hurt, frustration and sadness and for some it led to wives exhibiting increased suspiciousness about their presence in the house, resulting in some episodes of
physical aggression against them. Some husbands described that the primary relationship of husband and wife had changed to that of parent and child. Changes associated with dementia also resulted in communication difficulties and cessation of sexual relations. This finding is consistent with Narayan et al.’s (2001) that male carers experienced relational deprivation, although these authors were describing husbands’ experiences more broadly. Kramer & Lambert (1999) also reported that male carers experienced communication problems. In stage two of the present study several questions addressed the issue of changes in the husband-wife relationship associated with care giving. From the regression analysis, where care giving had resulted in changes in the husband-wife relationship, husbands experienced more burden but not more depression.

When the contribution of significant variables was examined and regressed on depression, effects of care giving on the relationship was found to contribute more to the variance of burden (11%) with changes in feelings towards spouses contributing less (4.3%) to the variance of depression.

From a descriptive analysis of item six in the Barriers of Caregiving Index (Kaye & Applegate, 1990a.), quality of past relationships with spouses indicated that over 20% of husbands reported that the quality of past relationships limited the amount of care giving they provided ‘To some extent’ and more than two thirds reported that it was affected ‘Very much’. Possible explanations for deterioration in the husband-wife relationship included communication difficulties, changes in
ability of wives to engage in sexual activity, wives’ loss of interest in everything, wives’ suspiciousness and wives no longer seen as spouses and mates, but children.

The finding that care giving affected the husband-wife relationship significantly is consistent with the findings of Kramer & Lambert (1999) and Narayan et al. (2001) who similarly found that care giving led to negative changes in the marital relationship.

8. 3.3 Research Question 3: What Supports did Husbands’ Utilise and What was their Evaluation of Them. What was the Effect of Husbands’ Use or Non-Use of Them in relation to Burden and Depression?

The study findings in relation to the research question will be discussed in the next section.

8. 3.3.1 Effects of Informal Support on Husbands’ Burden and Depression

From stage one data it was found that family members, friends and neighbours provided support for husbands in their care giving role. Mostly support was helpful and gratefully received. However, some wives were suspicious of friends and neighbours and neighbours were not always helpful or able to assist, for example, sometimes neighbours were from other countries and this made
communication difficult. However, support from family members varied and a few husbands didn’t have good relations with some of them. Overall, this finding was consistent with that of Braithwaite (1990) who reported that male carers did not always receive moral support from their family. Generally, family members provided both direct and indirect support. One of the effects of care giving on some husbands was a lack of social integration with friends not visiting as much and fewer invitations to dinner and to stay over. This is a similar finding to that reported by Kramer & Lambert (1999) and Almberg et al. (1998) that male carers experienced a lack of social support from others.

In stage two of the study several support variables were regressed on husbands’ burden and depression scores but no variables were significantly correlated with burden or depression.

From stage one findings, more than half of the husbands in the study attended Alzheimer’s Association support groups and a higher proportion attended in stage two. Mostly, husbands’ experiences with support groups were positive and beneficial. However, this was not always so and this is a phenomenon that support groups should examine more closely. It could be, for example, that where possible support groups specifically for husbands should be established. In stage two of the study support group attendance was regressed on husbands’ burden and depression scores but no variables were found to be significantly correlated with burden and depression. Moreover, support group ‘met expectations’ was not
significantly correlated with husbands’ burden or depression scores. However, where support groups were less helpful in providing emotional support, husbands experienced more burden. In addition, husbands who had attended less support groups experienced more depression. Attending a support group, helpfulness of the information provided by support groups, how helpful emotionally and ‘extent to which support groups met expectations’ was not significantly correlated when regressed on husbands’ depression scores.

8.3.3.2 Effects of Formal Support on Husbands’ Burden and Depression

From stage one results it was evident that husbands utilised a range of services including respite care, day care, home care, support groups, hospital services, community nurses and meals on wheels. A similar finding was reported by Barusch & Spaid (1989) and Brown, Williams, Mitchell & Brown, (1991). Braithwaite (1990) found that Meals on Wheels was more likely to benefit husbands but in the present study, Day Care was the most used service and was positively appraised by most husbands with few husbands utilising meals on wheels services. Community nurses provided a variety of services and were generally well received. The benefits derived from community nurses’ visits were also highlighted by Collins & Jones (1995).

Husbands identified a range of services that could be utilised but were not being utilized by them at the time of data collection. These included various respite
arrangements, more family involvement and assistance with wives’ activities of daily living requirements. This finding is at odds with those of Coe & Neufeld (1999) who reported that husbands lacked information about support services and did not know where to go for help.

Findings, however, in the present study are consistent with those of Miller (1987) who reported that male carers only occasionally used paid cleaning or neighbourhood help, as husbands in the present study received little help with housework, laundry and cooking. Husbands used a small range of formal services and assistance. It seems that routine care was carried out by husbands and that nursing and other services were received from time to time or as needed. This finding is consistent with that of Vinick (1984) who found that husband-carers accepted primary responsibility for care giving although they did receive some help from others.

Mostly, husbands found support to be helpful although this was not always so. In stage two, increased burden and depression occurred where husbands found it difficult to contact relatives and friends who presumably would be expected to provide support and assistance in relation to care giving.

The remaining sections evaluates the research employed in stages one and two, discusses the implication of findings for health professionals who are providing care for older husband-carers.
8. 4 Reflection on the Research Process

The volume of data generated through the use of both study designs was considerable but as the study progressed and as the data were analysed the researcher was able to build on the little that was known to provide a wider understanding of the experience of husbands caring for their spouses with dementia.

The following paragraphs touch on some of the methodological issues which arose in this study, and which are likely to be common for many researchers in a similar situation.

8. 4. 1 Stage One of the Study

Through the interviews intimate confidences and feelings were shared and sometimes this led husbands to be overcome with emotion. This is not an uncommon occurrence in sensitive areas of research, and must be anticipated when applying for ethical clearance, where protection of vulnerable informants is mandatory and counselling made available as needed. One possible approach is to discuss the possibility of emotional distress with each participant before the interview, and to indicate that the interview can and will be stopped at any time the informant is uncomfortable. It is also encumbent on researchers to observant throughout in the event that emotional upset occurs. Counselling was offered if
required. The consent to participate in research automatically includes agreement for the participant to withdraw from a study at any time, without explanation or repercussions.

Qualitative interviewing techniques are designed to assist disclosure of information, allowing for researcher prompts and for deeper exploration of issues relevant to the broad research question. Researchers are necessarily sensitive to the possibility of informants becoming emotionally aroused, which may or may not lead to a catharsis of sorts. This data gathering approach requires perceptive, empathic and above all, ethical management. In this instance, the approach facilitated the expression of husbands’ experiences and added to the richness of the data. Occasionally, a limited degree of self-disclosure on the part of the researcher using this approach may result in more open, honest and meaningful information being divulged. Consequently, it is important that the researcher maintain a neutral demeanour in relation to the information being disclosed by informants, yet be sufficiently empathic to encourage open disclosure. There must always be an option to offer to discontinue the interview, or to come to that decision alone, as distinct from relying on a distressed and vulnerable informant to make that decision.

The qualitative data collected in stage one provided a rich understanding of husbands’ experiences. It informed the development of stage two of the study. Care giving was revealed as a significant life experience for husbands, with the
complexity and uniqueness of each husbands' experience, as well as similarities of experience, made evident.

8. 4. 2 Stage Two of the Study.

Although the collection and analysis of quantitative data for Stage Two was anticipated to be more straightforward and manageable than the qualitative study, the researcher was confronted with complex decisions relating to subject numbers, clustering of the variables of interest into cohesive and logical groups, and the type of analysis that was eventually utilised as described in Chapter Four. This may have led to type 1 errors.

8. 5 Professional Implications of the Findings in Relation to Husband-Carers

The findings of this study should alert all professionals involved in this area of professional practice to the assessment of a husband-carer’s past relationship with their spouse, since it is clear that this can influence their attitude toward the care giving role. This empathy-generating step may in itself be therapeutic, but an understanding of the historical context in which care giving occurs can assist in determining which interventions might be most helpful to each of them. For example, many husband-carers can be assured that respite care can relieve some of the objective burden and may, therefore, benefit both the carer and the care recipient. The health professional may also need to work with carers to untangle
the web of emotions that they experience associated with care giving.

Encouragement to maintain outside interests may help carers to deal with the problems of care giving and alleviate feelings of burden, particularly if short-term and episodic respite care can be arranged. Attendance in a caregiver support group provides care givers with a sense of respite and the opportunity to share knowledge and care giving skills, as this and other research shows.

Health professionals who have contact with husbands who are providing care should be aware of services and benefits and should put them into contact with the appropriate service or organisation (for example, a support group). Carers need information about services that are accessible in their community and elsewhere. Information provision is a critical need for carers as it has the potential to promote family carer independence and autonomy. Information must be relevant to their situation and presented in a language they can understand, as suggested by Department of Health and Community Services (1995). Support for other family members should also be considered.

There was some evidence particularly in stage one of the study which suggested that husbands experienced lack of support of family members and in some cases, adult children were somewhat hostile about their fathers’ care giving effort, interpreting care giving activities to taking over their mothers’ normal responsibilities. Future studies could examine the role of conflict within the family network especially as a predictor of burden and depression.
Care giving for those husbands who reported that a pension was their main source of income may need special tax concessions, to offset the considerable expense associated with home-based care giving. In addition, greater flexibility in the workforce would aid care givers’ access to employment opportunities, at least in the earlier stages of dementia. Being able to keep in touch with spouses by phone and other means would support the carer in balancing work and urgent family commitments. In addition, a flexible sick leave policy and working hours would also assist.

Family carers should also be involved in service provision planning and in development and referral. Family members must be allowed to define their own needs and explore options to meet them. Such a focus will actively encourage consumer feedback and adapt service provision to respond accordingly.

8.6 Particular Implications for Nursing

Although this was not a nursing research study as such, nevertheless, as the present writer is a nurse by profession and teaches nurses in under-graduate and post-graduate nursing courses, it seemed relevant to highlight some of the implications for nursing practice that arise from study findings. Other related issues will be highlighted.

Four issues for nursing practice were evident from the study findings.
1) Ongoing Assessment of Carers and Care Recipients

Nurses are in a unique position to assess the needs of carers and the person being cared for. From study findings many male carers were feeling burdened and some were depressed. Nursing assessment, therefore, should include identifying those male carers who are ‘at risk’ of developing significant mental health problems. Because of the age group, it should also include assessment of carers’ age-related and physical health changes over time and care recipients’ physical status and the progress of their dementing illness.

There was some evidence from stage one findings that suggested that nurses did not always follow-up carers and wives once a diagnosis had been made, or that where they did that this was somewhat irregular in occurrence. It seemed clear from study findings that the aim of many home visits by nurses did not incorporate a holistic assessment of ‘the total care giving situation’, including any mental health problems that male carers might have been experiencing, but was perceived by carers to be unplanned and vague in their purpose. Findings suggested that nurses who visit carers at home, or meet and observe them at support group meetings, should assess their mental health needs in an ongoing way. This might include the use of standardised measures of, for example, depression or burden, and this will mean that nurses will need appropriate training in their selection (as there are several available), use and interpretation of the findings.
2) Nursing Interventions

An understanding of what nursing interventions male carers find beneficial to support their own care giving effort is needed. This was not evident from study findings and husbands did not always know why nurses visited them. On some occasions they were able to provide advice about difficulties being experienced but this was very ad hoc. Finding out what interventions work or don’t work, with particular male carers, would assist nurses in their supportive role for carers and their wives.

Other interventions that could be utilised by nurses to support carers and their wives include telephone services, education, wellness groups, mens’ and other support groups (Alzheimer’s support groups), day and respite care, and cognitive-behaviour therapy (CBT). The effectiveness of visiting versus telephoning for carers has not been investigated in the research literature. In the present study, carers reported that nurses would ring them to check on ‘how they were going’ in relation to their care giving activities and experiences. Although there is a place for this open-ended approach, better clinical practice is associated with utilising a more organised and holistic approach in which the nurse has a list of questions in mind to work through to complete a more thorough assessment of the care giving situation for both the carer and person being cared for.

From stage one it was evident that older husband-carers had few confidantes,
therefore nurses may need to encourage men to seek out personal support systems that include more than one friend or family member. Education should be provided throughout the entire care giving cycle. All older male carers should be encouraged by nursing staff to identify and participate in a wellness programme to assist them to continue to take care of their wives. Wellness programmes may be offered by hospitals or community health centres and focus on relaxation and stress reduction techniques, provide information about good nutrition and exercise programmes in a social context to facilitate learning and socialisation with others.

Research into the effectiveness of early interventions, mens’ and other support groups might also be informative. There was some evidence to suggest that male carers benefited from support groups but this was not always the case and this should be further evaluated to identify what elements are most effective for males. The nurse’s role in relation to support groups requires further attention. There was evidence from the study that day care and respite care provided effective supports for male carers. However, the effectiveness of respite care should be further researched as it is uncertain which aspects of day care and respite care are most effective, and whether in-home, or overnight or residential care is more effective. In addition, the role of the nurse in relation to these two support services has not been researched.

To effectively utilise cognitive behaviour therapy, nurses will require appropriate training as well as clinical supervision. Some males had difficulty accepting the
diagnosis that was made and the prognosis associated with it. These men may be suitable candidates for CBT. The effectiveness of this approach with male carers would also need to be evaluated and not all males will benefit from this intervention.

The nurse should also act as enabler so that the care giver is able to do things and make decisions about their needs for themselves. This point highlights the trend over recent years toward user participation in the planning of care. Clearly, the extent of the carer’s participation in care planning may be limited by the extent of care that they have to provide on a day to day basis. The nurse’s role will be to act as carer-enabler and facilitate the carer’s involvement in decision making related to wives’ management, including at what stage to place wives in a residential facility.

Improvement in nurses’ understanding of which interventions would be helpful, for whom and at what point during the care giving career, could potentially lead to three desirable outcomes: better case management; reduction of costs associated with unnecessary nurse involvement; and/or reduced admission, or readmission of the family member with dementia to hospital or nursing home care.

Overall, it can be stated that there is a lack of research describing the ways in which nurses deliver care for family members with dementia and their carers.
3) Training to Manage Wives’ Problem Behaviours

Carers should receive training in techniques for managing wives’ problem behaviours. From the literature review it was evident that psychoeducational group interventions were effective in decreasing care givers’ perceptions of the difficulties that they were faced with, including care recipients’ problem behaviours. There was no evidence from the study that any carers had attended a psychoeducational group. The nurse’s role here might be to identify the availability of such groups and encourage carers to attend where they are available. Alternatively, nurses could adapt the components psychoeducational group interventions, including education of the carer and other family members, family support (Hepburn, Lewis, Tornatore, Sherman & Bremer, 2007), for example, through education, and provision of ideas about how to reduce wives’ problem behaviours. It has been shown that strengthening carers’ knowledge, skills, and outlook for care giving (‘training for the role’), could ameliorate the negative effects associated with care giving. Training could also include ideas about how carers can better self-manage. The latter might include assisting carers to develop stress management techniques. This presupposes that nurses must receive training in these techniques.
4) Family Support

In their attempts to assist the carer, nurses in this field of practice must not overlook the needs of, or inadvertently marginalize, the family member with dementia. Family-oriented nursing care should include care to both the carer and the person with dementia.

Nurses will need to develop approaches to bring family members into contact with specialist services in the event that others, for example, General Practitioners (GPs), may ignore the concerns or attribute the family member’s illness to old age. From the interview findings in stage one, there was some evidence that a few family GPs had downplayed or even not recognised the significance of changes in wives’ behaviour when they assessed them. This issue becomes increasingly important in the early stages of dementia. Another role for nurses, might include liaising with GPs to facilitate their understanding of dementia and a greater awareness of available relevant services. The extent to which family GPs continued to be involved in carer- and care-recipient care in the study was unknown but should be the focus of further research efforts. The role of the nurses in relation to working with family GPs to provide ongoing care for family carers and those receiving that care was also unknown.
Study participants use of support groups

The use by study participants of formal supports was relatively low although some husbands identified that they needed services but were not currently using them. Further investigation would be needed to determine if there were any barriers to their access to, or utilisation of services. Barriers, for instance, might include associated expenses. We know that some carers reported that a pension was their main source of income and for these husbands, accessing and utilizing services might have represented a significant cost to them. Access and acceptability of services may be found to be other impediments to services utilisation. For some husbands, access to services may have been affected by the pattern or extent of their care giving responsibilities, or by lack of knowledge about available services, or be related to living in rural area where services were less available. Services may not have been acceptable to husbands if they have been perceived as being too intrusive, or as inappropriate for their needs, or as threatening to their sense of control. Nurses and other health care professionals should consult with husbands to determine what services are both appropriate and acceptable.

8. 7 Summary and Conclusion:

Researchers need to be true to the philosophical, epistemological and methodological underpinnings of their chosen research approach, and to provide evidence of research rigour at all stages. Effective supervision of the research
process supports those new to an investigative methodology in conducting studies that are marked by ethical, procedural and analytic rigor.

8. Evaluation of Stage One of the Study

Procedures for inclusion of stage one informants, including the sample size and relevant characteristics, were consistent with the chosen qualitative /interpretive methodology. Findings from such modes of investigation require applicability of findings to those in generally similar contexts, as distinct from statistical generalisability. Most importantly in interpretive research, study informants need to be able to recognize core findings as being closely applicable to their own experience. Where analysis has yielded parsimonious theoretic results, core findings can achieve a wider applicability.

Data analysis and interpretation of Stage One interviews yielded rich descriptive and theoretical findings which, had the study been completed at that point, would still have contributed significantly to an understanding of the day to day experiences of husbands caring for their wives with dementia. These insights can assist professionals, both group and individuals, to broaden their appreciation of the pressures on, and the challenges facing, older male spouses in this situation, and potentially, to work creatively to provide some timely relief.
Additionally, and possibly of equal significance, the Stage One study findings hopefully will have a wider applicability among professional and non-professional carers, for those becoming increasingly dependent on others in all daily living activities.

8.9 Evaluation of Stage Two of the Study

Although the sample used in Stage Two was relatively small, at the time this study was conducted the researcher was advised by an expert researcher into male care giving in dementia care that the data set was statistically acceptable. Future studies of husband-carers could include a preliminary power analysis to determine an acceptable sample size, to detect true effects as suggested by Polit & Beck (2004). This would enhance the statistical conclusions and validity of future studies of husband-carers. In addition, further studies should aim to include greater numbers of husband-carers from rural and remote and various ethnic and racial backgrounds, thus contributing to the generalisability of statistical findings.

A possible limitation of the present study, is that informants were self-selecting from support groups, community agencies, and other formal sources. Such a selection pattern raises questions about the statistical representativeness of the sample group. Additionally, the stage two questionnaire and standardised measures that husbands were asked to complete, may have been too time-consuming. The researcher was conscious of this issue and encouraged
participants not to rush the process of completing the paperwork and it was suggested that participants complete some of the paperwork each day until all items were answered. This approach is recommended by the present writer where older study participants are required to complete questionnaires and measures.

The focus of the present study has been on the husband-carer as distinct from the total support network, so that further opportunities for research exist in this direction. More needs to be known about the care giving experiences of those who do not attend support groups or what contacts with formal services occur, as the perceptions of experiences and needs of these groups might be different.

Limitations to studying the effects of religion/spirituality on carers’ experiences include: (1) caregivers in the present study might have been healthier and with better adaptation skills than those who had opted out of the role; (2) measure of religion/spirituality coping in the present study were two single items one of which was isolated from a longer scale. In the future, researchers should include a more comprehensive measure of religion/spirituality to examine the effect of these phenomena on husbands’ care giving experiences and responsibilities. A third consideration was that the husbands in this study were predominantly white and of Anglo-European origin and there were nearly twice as many Australian-born as overseas-born participants. It could be, for example, that had care giving experiences of husbands who were born overseas been examined, they could have perceived religion/spirituality as a much more important issue than Australian
born husbands. Despite these potential limitations, it has been instructive to observe that religion/spirituality played a role in this generation of caregivers.

As this was an Australian study, the extent to which the findings could be relevant to husband care givers in other countries is uncertain. However, it is possible that the findings from the present study will have broad applicability in similar cohorts and in similar circumstances in other countries, despite language differences.

This study employed a cross-sectional design and provides a picture of husbands’ care giving experiences at a point in time. As Schneider et al. (2004) note, the results of cross-sectional studies should be used as baseline measures for longitudinal and intervention studies. Future studies of husbands’ care giving experiences could benefit from examining husbands’ experiences over time.

When the researcher examined the internal reliability of the measures employed in Stage Two of the study, some problems were identified. Zarit Burden Scale (Zarit et al., 1986), Beck Depression Inventory (Beck et al., 1961) and Jalowiec Coping Scale (Jaloweic et al., 1984) all achieved reasonable Cronbach alpha values. However, the sub-scale Instrumental traits of the Sex Role Inventory (Bem, 1974) had a Cronbach alpha of only 0.46. One possible interpretation of this finding is that this scale may not be appropriate for older husbands-carers. A more appropriate scale should be used for this group of carers, or possibly there is a need to develop one.
CONCLUSION

Examining husbands' care giving experiences using qualitative and quantitative paradigms facilitated the development of research and critical skills by the researcher. Utilising both designs has generated increasing confidence in working with qualitative and quantitative designs, alone or in combination. Moreover, utilising both designs in combination has facilitated an in-depth understanding and appreciation of the experiences of husbands who chose to provide day-to-day care for their wives at home who had been diagnosed with dementia.
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APPENDIX ONE

PARTICIPANT INFORMATION SHEET

“DEMENTIA: MALE CAREGIVERS’ EXPERIENCES ASSOCIATED WITH PROVIDING CARE FOR A FAMILY MEMBER AT HOME WITH DEMENTIA”

Dementia presently affects 5.6% of the Australian population at age 75 to 79 and up to 23.6% of those over 85. It is a particularly devastating disease. For many people with dementia, the main caregiver is the family. In some families, the caregiver is an older male spouse (over 65 years of age). This role can be particularly time consuming, expensive and exhausting. There is reason to believe that males’ experiences of caregiving may be different to that of female caregivers.

There are few overseas studies of male caregivers’ experiences generally and fewer studies in the Australian context. I have conducted several other caregiver studies and these have been published in nursing and other journals. In addition, I have been able to present the findings at various conference presentations. This has provided greater insights for health professionals into the needs and problems of caregivers. I have also provided participants in studies with written feedback about study results.

The purpose of this study is to increase our understanding of the needs and problems of male spouse caregivers, the reasons for taking on the role, how they feel about the role, what caregiving activities they carry out, and what supports they have.

I am seeking older male spouse caregivers, therefore, who will participate in this study. If you volunteer, I will forward a questionnaire for you to complete and return to me by Free Post so that there will not be any expense to you. Your name is not required on the questionnaire although the questionnaire will be numbered and I will be the only person who will be able to identify you from your personal ID number. This will allow me to identify who has sent back the questionnaire and make follow up easier.

Sometimes caregivers can become upset when answering some of the questions in the questionnaire. If this occurs, I would only be too pleased to talk with you. Alternatively, you may wish to speak with your own GP or a member of the Aged and Extended Care Team (I would be able to provide a contact telephone number).

Please note that you have the right to withdraw from the study at any time after giving your consent to participate.

Peter Brown
Senior Lecturer
Faculty of Nursing
The University of Sydney
Tel. No. 6466249 (work)
8964171 (home)
APPENDIX TWO

INFORMED CONSENT

I, ___________________________________________ hereby voluntarily consent to

participant in the research entitled:

"DEMENTIA: MALE CAREGIVERS' EXPERIENCES ASSOCIATED WITH PROVIDING
CARE FOR A FAMILY MEMBER AT HOME WITH DEMENTIA"

I understand that the information obtained from this research may be shared with others (for example, through professional publications and conference presentations). However, my right to privacy will be retained by the researcher, that is, I will not be able to be identified individually. Information about the research study is provided in the attached Participant Information Sheet and has been explained to me by the researcher, and I understand what is expected of me.

I also understand that I can withdraw from the study at any time after I have given my consent to participate.

Signed by the participant: ____________________________________________

Date:      __________________________

Witness: __________________________ (Name)

__________________________ (Signature)

__________________________ (Date)

Peter Brown
Senior Lecturer
Faculty of Nursing (Cumberland Campus)
The University of Sydney
Tel. no.646-6249 (Work)
896-4171 (Home)
APPENDIX THREE

QUESTIONNAIRE FOR MALE CARE GIVERS OF SPOUSES WITH DEMENTIA AT HOME

Questionnaire No.________

CARE GIVER PROFILE

A. BIOGRAPHICAL INFORMATION

Please answer the following questions about yourself and your spouse

1. What is your age in years? ______

2. Where were you born? _____________________________

3. What is your present marital status? ___________ _________

4. What is the highest level of education you have obtained? __________________________________________________________________________

5. What is your religion? (if any)_________________ ________

6. How close is your emotional relationship with the impaired family member? (Circle a number)

1  2  3  4  5
Distant                  Very Close
7. What other household residents live with you? (do not include your spouse)
________________________________________________________________________

8. If there are other household residents, what, if any help, do they provide?
________________________________________________________________________
________________________________________________________________________

9. Are you employed? ____ yes ____no

10. If you are employed, what is your present job?
____________________________

11. What is your main source of income?
________________________________________________________________________

B. CARING RESPONSIBILITIES

12. Approximately what percentage of the health care costs for your spouse are paid by you?
_________ percentage (%) of total costs

13. Of all the care giving responsibilities, approximately what percentage do you feel that you provide for your spouse? _______ percentage (%)

14. How many hours per day are you involved in providing direct and indirect care to the impaired family member?
      _____ hours in direct care
      _____ hours in indirect care

15. How long have you been providing care for your spouse? _________
16. If there has been a change in your physical health status, to what extent is this related to your role as a care giver? (place a cross on the line)  
1______________________________________________________________5  
Not at all             Totally  
17. If there has been a change in your emotional status, to what extent is this related to your role as care giver? (place a cross on the line)  
1______________________________________________________________5  
Not at all             Totally  
18. To what extent have your feelings changed toward your spouse since the onset of the problems? (place a cross on the line)  
1______________________________________________________________5  
Not at all             Totally  
19. If your feelings have changed, briefly describe the changes that have taken place  
______________________________________________________________  
______________________________________________________________  
20. What are your three most important needs related to your role as primary care giver?  
1.______________________________________________________________  
2.______________________________________________________________  
3.______________________________________________________________  
21. Do you presently attend a support group? (eg., Alzheimer's Association) (Tick one)  
_____ Yes  
_____ No
22. How helpful has the group been to you in providing KNOWLEDGE/INFORMATION to assist you in the care giving role? (Circle a number or tick a response below))

   1  2  3  4  5
   Not at all          Very helpful
   helpful
   ______ Too soon to tell
   ______ Don't know

23. How helpful has the group been to you in providing EMOTIONAL SUPPORT as a care giver? (Circle a number or tick a response below)

   1  2  3  4  5
   Not at all          Very helpful
   ______ Too soon to tell
   ______ Don't know

24. How many relatives or friends regularly attend these meetings with you?
   _____ relatives               _____ friends

25. Approximately how many group meetings have you attended? _______

26. The support group meets my expectations: (Tick one)
   _____ (1) Most of the time
   _____ (2) Some of the time
   _____ (3) Very little of the time
   _____ (4) None of the time
   ...... _____ (5) Too soon to tell
27. What do you like most about the support group?

____________________________________________________________________________________
____________________________________________________________________________________

28. What do you dislike most about the support group?

____________________________________________________________________________________
____________________________________________________________________________________

C. CARE GIVER SUPPORT

29. How many relatives or friends are available to provide support for you in your care giving responsibilities?
   _____ relatives
   _____ friends

30. How easy is it for you to contact these people? (Circle a number)

   1       2       3       4       5
   Very easy
   Very
   Difficult

31. Of all of these people, is there one specific person that you can share your most personal thoughts and feelings with?
   _____ Yes
   _____ No

32. If your answer to the previous question was "Yes", is the person readily available?
   _____ Yes
   _____ No
33. To what extent do you feel that your religious beliefs and practices assist you to cope with the care giving role? (Circle a number)

1  2  3  4  5
Not at all       Totally

D. CARE GIVER ROLE

34. To what extent do you feel that your upbringing has prepared you for the care giving role? (place a cross on the line)

1__________________________________________________________5
Not at all       Totally

35. If you feel that your upbringing experiences helped prepare you for your present care giver role, what was it about those experiences that were so helpful?

__________________________________________________ ___________
__________________________________________________ ___________

36. Why did you take on the care giver role?

_____________________________________________________________
__________________________________________________ ___________

37. To what extent, if any, has care giving affected your relationship to your spouse? (place a cross on the line)

1____________________________________________________________5
Not at all       Totally

38. If your relationship has changed, please describe what the changes have been

_____________________________________________________________
_____________________________________________________________
39. Have you had any previous experiences providing care (eg. regular responsibility for children)?
   ____ yes
   ____ no

40. If your answer to the previous question was "yes", to what extent were such experiences helpful for your present role as care giver? (place a cross on the line)

   1_________________________________________________ ___________5
   Not at all         Totally

41. What aspects of care giving do you like/dislike?

   Like:
   ________________________________________________________________

   Dislike:
   ________________________________________________________________

42. To what extent do you see care giving as being like a job? (place a cross on the line)

   1______________________________________________________________5
   Not at all         Totally

43. Are there any aspects of the care giver role like the job that you used to do?
   ____ yes
   ____ no
   ____ don't know

44. If your answer to the previous question was "yes", in what ways is care giving like the previous roles that you carried out in your job?

   ________________________________________________________________
45. To what extent have the experiences in your previous job helped you to carry out your present caregiver role? (place a cross on the line)

1___________________________________________________________5
Not at all Totally

46. To what extent do you think that it is important to be efficient and organised on a day-to-day basis? (place a cross on the line)

1___________________________________________________________5
Not at all Totally

47. To what extent do you think that your present role is an important one? (place a cross on the line)

1___________________________________________________________5
Not important Extremely important

E. COMMUNITY SUPPORTS AND SERVICES

48. Do you know of any supports and services which are available to help you with your caregiving responsibilities?

_____ (1) Yes
_____ (2) No
_____ (3) Don’t know

49. If your answer was "Yes", what are they?

______________________________________________________________
______________________________________________________________
50. If there are services that you know of, have you made use of them? (Tick one and elaborate where appropriate)

   _____ (1). No  Why not? __________________________________________

   _____ (2) Yes  a) Which services?

                           __________________________________________
                           __________________________________________

   b) How often do you use them?

      _____ (1) Not very often
      _____ (2) Sometimes
      _____ (3) Regularly

51. What types of community services would you most like to assist you in your care giving role?

                           __________________________________________
                           __________________________________________

**IMPAIRED SPOUSE**

**A. BIOGRAPHICAL PROFILE**

52. Age of spouse in years ________

53. Where was your spouse born? _______________________

54. What is the highest level of education your spouse has attained?

                           __________________________________________

55. What was your spouse's main occupation?

                           __________________________________________

56. What are your spouse's main sources of financial support?
57. Where does your spouse live? ________________________

58. How long has she lived at this location? ____________

59. How long ago did you first notice changes in your spouse's behaviour?
_________________________________________________

60. What were the first changes in behaviour state that you noticed?
_________________________________________________
_________________________________________________

61. When was the impairment first diagnosed by a doctor? 19______

62. What was the diagnosis? ____________________________

63. How would you describe the course of your spouse's illness? (Tick one)

   ___ (1) Gradual       ___ (2) Moderate       ___ (3) Rapid
deterioration         deterioration         deterioration

• ADAPTED WITH PERMISSION FROM THE CARE GIVER QUESTIONNAIRE, CENTRE FOR GERONTOLOGY, THE UNIVERSITY OF UTAH
APPENDIX FOUR

Zarit Burden Caregiver Assessment

Instructions: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers. Check the response which best reflects how you feel.

Statements

1. Do you feel that this person asks for more help than he/she needs?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

2. Do you feel that because of the time you spend with this person that you don’t have enough time for yourself?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

3. Do you feel stressed between caring for this person and trying to meet other responsibilities for your family or work?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

4. Do you feel embarrassed over this person’s behaviour?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

5. Do you feel angry when you are around this person?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

6. Do you feel that this person currently affects your relationship with other members or friends in a negative way?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

7. Are you afraid of what the future holds for this person?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

8. Do you feel this person is dependent on you?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

9. Do you feel strained when you are around this person?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

10. Do you feel your health has suffered because of your involvement with this person?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

11. Do you feel that you don’t have as much privacy as you would like because of this person?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>
12. Do you feel that your social life has suffered because you are caring for this person?

13. Do you feel uncomfortable about having friends over because of my wife?

14. Do you feel that your wife seems to expect you to take care of her as if you were the only one she could depend on?

15. Do you feel that you don't have enough money to care for your wife, in addition to the rest of your expenses?

16. Do you feel that you will be unable to take care of this person much longer?

17. Do you feel you have lost control of your life since your wife's illness?

18. Do you wish you could just leave the care of your wife to someone else?

19. Do you feel uncertain about what to do about your wife?

20. Do you feel you should be doing more for your wife?

21. Do you feel you could do a better job in caring for your wife?

22. Overall, how burdened do you feel in caring for your wife?

Please provide any additional comments for this section that you might like to make.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

(Zarit, Todd & Zarit, 1986)
APPENDIX FIVE

Beck Inventory

Below are groups of statements. Please read each group of statements carefully. Then pick out the statement in each group, which best describes the way you have been feeling the PAST WEEK, INCLUDING TODAY! Circle the number beside the statement you picked. If several statements in the group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.

1. 0 I do not feel sad
   1 I feel sad
   2 I am sad all the time and I can’t snap out of it
   3 I am so sad or unhappy that I can’t stand it

2. 0 I am not particularly discouraged about the future
   1 I feel discouraged about the future
   2 I feel I gave nothing to look forward to
   3 I feel that the future is hopeless and that things cannot improve

3. 0 I do not feel like a failure
   1 I feel that I have failed more than the average person
   2 As I look back on my life, all I can see is a lot of failures
   3 I feel I am a complete failure as a person

4. 0 I get as much satisfaction out of things as I used to
   1 I don’t enjoy things the way I used to
   2 I don’t get real satisfaction out of anything anymore
   3 I am dissatisfied or bored with everything

5. 0 I don’t feel particularly guilty
   1 I feel guilty a good part of the time
   2 I feel guilty most of the time
   3 I feel guilty all of the time

6. 0 I don’t feel I am being punished
   1 I feel I may be punished
   2 I expect to be punished
   3 I feel I am being punished

7. 0 I don’t feel disappointed in myself
   1 I am disappointed in myself
   2 I am disgusted with myself
   3 I hate myself
8. 0 I don’t feel I am any worse than anybody else
    1 I am critical of myself for my weaknesses or mistakes
    2 I blame myself all the time for my faults
    3 I blame myself for everything bad that happens

9. 0 I don’t have any thoughts about killing myself
    1 I have thoughts of killing myself, but I would not carry them out
    2 I would like to kill myself
    3 I would kill myself if I had the chance

10. 0 I didn’t cry anymore than usual
    1 I cry now more than I used to
    2 I cry all the time now
    3 I used to be able to cry, but now I can’t cry even though I want to

11. 0 I am no more irritated now than I ever am
    1 I get annoyed or irritated more easily than I used to
    2 I feel irritated all the time now
    3 I don’t get irritated at all by the things that used to irritate me

12. 0 I have not lost interest in other people
    1 I am less interested in other people than I used to be
    2 I have lost most of my interest in other people
    3 I have lost all of my interest in other people

13. 0 I make decisions about as well as I ever could
    1 I put off making decisions more than I used to
    2 I have greater difficulty in making decisions than before
    3 I can’t make decisions at all anymore

14. 0 I don’t feel I look any worse than I used to
    1 I am worried that I am looking old or unattractive
    2 I feel that there are permanent changes in my appearance that make me look unattractive
    3 I believe that I look ugly

15. 0 I can work as well as before
    1 It takes an extra effort to get started at doing something
    2 I have to push myself very hard to do anything
    3 I can’t do any work at all
16. 0 I can sleep as well as usual
   1 I don’t sleep as well as I used to
   2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
   3 I wake up several hours earlier than I used to and cannot get back to sleep

17. 0 I don’t get more tired than usual
   1 I get tired more easily than I used to
   2 I get tired from doing almost anything
   3 I am too tired to do anything

18. 0 My appetite is no worse than usual
   1 My appetite is not as good as it used to be
   2 My appetite is much worse now
   3 I have no appetite at all anymore

19. 0 I haven't lost much weight, if any lately
   1 I have lost more than 5 Pounds
   2 I have lost more than 10 Pounds
   3 I have lost more than 15 Pounds
   ➜ I am purposely trying to lose weight by eating less (Circle yes or no)
   Yes/No

20. 0 I am no more worried about my health than usual
   1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation
   2 I am very worried about physical problems and it’s hard to think of much else
   3 I am so worried about my physical problems, that I cannot think about anything else

21. 0 I have not noticed any recent change in my interest in sex
   1 I am less interested in sex than I used to be
   2 I am much less interested in sex now
   3 I have lost interest in sex completely
If there are any comments that you would like to add for this section please do so at this stage.

(Beck, Ward, Mendelson & Erbaugh, 1961)
APPENDIX SIX

**Jaloweic Coping Questions**

How often do you use the following attitudes or behaviours to cope with your role as a caregiver to a wife who has dementia. (Tick the box that best represents how you feel or what you do, for each question).

<table>
<thead>
<tr>
<th></th>
<th>Almost Always</th>
<th>Often</th>
<th>Undecided</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
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<td>2.</td>
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<td>3.</td>
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<td>7.</td>
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<td>8.</td>
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<td>9.</td>
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<td>10.</td>
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<tr>
<td>11.</td>
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<tr>
<td>12.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

1. Hope that things will get better
2. Try to maintain some control over the situation
3. Find out more about the situation so you can handle it better
4. Think through different ways to handle the situation
5. Look at the problem objectively
6. Eat; smoke
7. Try out different ways to solve the problem to see which works the best
8. Draw on past experiences to help you handle the situation
9. Try to find meaning in the situation
10. Pray; trust God
11. Get nervous
12. Worry
13. Break the problem down into 'small pieces'
14. Seek comfort or help from family or friends
15. Set specific goals to help solve the problem
16. Accept the situation as it is
17. Want to be alone
18. Laugh it off, figuring things could be worse
19. Try to put the problem out of my mind
20. Daydream; fantasise
21. Get prepared to expect the worse
22. Talk the problem over with someone who has been in the same situation
23. Actively try to change the situation
24. Get mad; curse; swear
25. Cry; get depressed
26. Go to sleep figuring things will look better in the morning
27. Don’t worry about it, everything will probably work out
28. Withdraw from the situation
29. Work off tension with physical activity
30. Settle for the next best thing
31. Take out your tensions on someone or something else
32. Drink alcoholic beverages
33. Resign yourself to the situation because things look hopeless
34. Do nothing in the hope that the problem will take care of itself
<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>35. Resign yourself to the situation because it is your fate</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>36. Do anything just to do something</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Blame someone else for your problem</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>38. Meditation; yoga; biofeedback</td>
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<tr>
<td>39. Let someone else solve the problem</td>
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<td></td>
<td></td>
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<tr>
<td>40. Take drugs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If there are any comments about this section that you would like to make please do so in the space provided below:

_______________________________________________________________________________

_______________________________________________________________________________

_______________________________________________________________________________

(Jaloweic, Murphy & Powers, 1984)
APPENDIX SEVEN

BEM SEX ROLE INDEX

I am interested to explore the extent to which personality traits affect your care giving experiences. For each of the following traits indicate the extent to which it describes you by placing a tick (✓) in the box opposite each trait.

<table>
<thead>
<tr>
<th>Personality Trait</th>
<th>Rarely or Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Usually</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggressive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loving</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analytical</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compassionate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yielding</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gentle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-sufficient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Warm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Bem, 1974)
APPENDIX EIGHT

Barriers to Caregiving Index

I am interested in the potential factors which serve to limit the amount of care men provide to their spouses. Responses should be based on your personal experiences of caregiving. For each of the following statements indicate the extent to which it describes you by placing a tick (✓) in the box opposite the statement.

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Not at all</th>
<th>Minimally</th>
<th>To some degree</th>
<th>Very much so</th>
<th>Doesn’t apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>The requirements of your job (if employed)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family obligations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The nature of your social life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your opinion as to what appropriate behaviour for men should be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The opinions of others as to what appropriate behaviour for men should be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of your past relations with your spouse should be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The general stress associated with caregiving</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The availability of other relatives &amp; friends who can provide care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your general health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The physical health of your spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The mental or emotional health of your spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personality changes in your spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your family’s tradition of helping others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The availability of community services for your relative</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Kaye & Applegate, 1990)
Clinical Dementia Rating Scale: Severity of Illness

This questionnaire has been designed to allow you the carer, to rate the degree of severity of the dementia that your wife has on six aspects of daily living. Please indicate which level your wife is functioning at by placing a cross (X) on the line at the appropriate place.

For example, on Memory, if your wife has moderate memory loss which interferes with her being able to function from day to day, then you would place a cross (X) at the appropriate level on the line.

- No loss
- Mild loss
- Moderate loss
- Severe loss

If your wife’s memory loss falls somewhere in between moderate and severe, then you would place a cross (X) as follows:

- No loss
- Mild loss
- Moderate loss
- X
- Severe loss
Now please rate:

1. **Memory**

   - No memory loss or slight occasional forgetfulness
   - Mild consistent forgetfulness, can only partially recollect events. Memory loss does not interfere much with everyday activities
   - Moderate memory loss, more marked for recent events; defect interferes with everyday activities
   - Severe memory loss. Can only remember material learnt long ago or after a great deal of practice. Unable to retain any new memory
   - Very severe memory loss. Only fragments of memory remain

2. **Orientation**

   - Fully orientated. Knows where she is, what day it is and what is going on around her
   - Difficulty in orientation with time. Unsure of day or date. However, does know who she is and where she is although she may still get lost
   - Has little idea of time and often has little idea where she is particularly if moved from similar surroundings. Still knows who she is and who the people around her are
   - Only knows who she is but has no idea at all where she is, what day it is or even what time it is
3. Judgment and Problem Solving

- Solves everyday problems well. Has good judgment in relation to past performances
- Only doubtful impairment in solving problems. Most of the time she can understand similarities or differences between things
- Moderate difficulty in handling complex problems. Still able to function socially and understands normal social functions
- Severely impaired in handling problems. Usually, fails to understand similarities or differences between things. Poor social judgment
- Unable to make judgments or solve problems

4. Community Affairs

- Independent function at usual level in job, shopping, business and financial affairs, volunteer and social groups
- Only doubtful or mild impairment, if any, in these activities
- Unable to function independently at these activities though may still be Engaged in some; may still appear normal to casual inspection
- No pretence of independent function outside home

5. Home and Hobbies

- Life at home, hobbies, intellectual interests well maintained
- Life at home, hobbies, intellectual interests well maintained or only Slightly impaired
- Mild but definite impairment of function at home, more difficult chores abandoned; more complicated hobbies and interests abandoned
- Only simple chores preserved; very restricted interests, poorly sustained
- No significant function in home outside of own room
6. Personal Care

- Fully capable of self care
- Needs occasional prompting
- Requires assistance in dressing, hygiene, keeping of personal effects
- Requires much help with personal care, often incontinent

If there are any comments that you would like to make about the changes in your wife’s behaviour that have taken place, please make them below:

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

(Berg, 1993)
APPENDIX TEN

Problem Behaviour Checklist

Please indicate by ticking the appropriate box how often your wife behaves in the following ways:

<table>
<thead>
<tr>
<th></th>
<th>Never or Hardly ever</th>
<th>Occasionally</th>
<th>Most of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Able to hold a sensible conversation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Able to dress without help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Demands attention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Uses bad language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Able to get in and out of bed without help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Disrupts personal social life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Able to wash without help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Physically aggressive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Needs help at meal times</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Incontinent of faeces</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Creates personality clashes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Temper outbursts</td>
<td></td>
<td></td>
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<tr>
<td>13.</td>
<td>Able to manage stairs</td>
<td></td>
<td></td>
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<tr>
<td>14.</td>
<td>Safe when outside house alone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Wanders about the house at night</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Wanders outside during the day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Can be safely left alone for an hour or more</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Incontinent of urine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Noisy or shouts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Always asking questions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Makes accusations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Able to get in and out of a chair without help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Vulgar habits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Forgets things that happened</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Likely to fall</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Rude to visitors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>Cares for own appearance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>Concerned about personal hygiene</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>Steady on feet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>Able to walk outside unaided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Zarit, Reever & Bach-Peterson, 1980)