

**THE PSYCHOLOGICAL HEALTH IMPLICATIONS OF SOCIAL
SUPPORT FOR THE ALZHEIMER CAREGIVER**

by

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DISSERTATION

submitted in fulfilment

of the requirements for the degree

MAGISTER ARTIUM

in

PSYCHOLOGY

in the

**DEPARTMENT OF PSYCHOLOGY
FACULTY OF HUMANITIES**

at the

UNIVERSITY OF PRETORIA

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MARCH 2007

Acknowledgements

My appreciation goes to

my friends and family for their support;

my study leaders Dr Nafisa Cassimjee and Ms Adri Prinsloo, without whom this study would not be possible, for their dedication to the study;

to all the Alzheimer caregivers for the phenomenal task that they are performing for the well-being of the greater society.

A special thanks goes to Rina Owen, Sollie Millard and the people from the Statistics department for the statistical analysis of the data.

The year 2004 will be marked as the year millions of people all over the world were moved by the film "THE PASSION OF THE CHRIST," which means nothing without acting thereon by showing compassion to our fellow human beings.

Abstract

Apart from the personal and socioeconomic burdens of dementia, the immense, intangible emotional and psychological suffering endured by dementia patients, their carers and families are difficult to quantify. Alzheimer's dementia (AD) accounts for over 50% of all dementias and is responsible for a large percentage of morbidity and mortality in older adults. It is also recognised as a disease qualitatively distinct from the normal ageing process. Identified almost 95 years ago by Alois Alzheimer, it poses a seminal problem, which in the twenty-first century is compounded by the predicted extension in human longevity. Caregivers thus bear a considerable financial, social and emotional burden due to the progressive debilitating nature of the disease. It is hypothesised that social support buffers the individual from the negative emotional effects of stressful circumstances associated with the caregiving process; and although the inevitable course of the disease cannot be stopped, improving support to caregivers may decrease feelings of isolation and improve psychological health. Caregivers of AD patients often report experiencing a lack of social support due to the nature and progression of this disease. This study thus aims to investigate the relationship between real and/or perceived social support and psychological health (depression, loneliness, and perceived burden of care) amongst a cohort of Alzheimer's caregivers. The following standardised measuring instruments were used to elicit data: the Zarit Burden Interview (ZBI), the Beck Depression Inventory (BDI-II), UCLA Loneliness Scale, Personal Resource Questionnaire (PRQ85) and a biographical questionnaire. Data were analysed using correlation and regression statistical techniques.

The main findings of this study were that there is a significant positive correlation between loneliness and depression; loneliness and personal strain (burden) as well as both role and personal strain (burden) with depression. A significant negative correlation was also found between perceived social support and loneliness. Additional findings were that participants with higher educational qualifications experienced more personal strain and role strain (burden); caregivers with patients in the two younger age groups scored higher on the BDI-II; and the cognitive status of the patient correlated with the burden experienced by the caregiver. A significant negative correlation between summaries of reactions (burden) and duration of caregiving was also reported.

Key words : Longevity; Alzheimer's; psychological health; morbidity; mortality; social support buffers; isolation; burden; loneliness; biographical; correlation and regression statistical techniques; intangible emotional and psychological suffering.

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CHAPTER 1

INTRODUCTION

Martin-Moreno (2005) states that population ageing has become a serious issue that requires urgent action. Projections indicate that ageing aggravates the magnitude of mental health problems, which has a major effect on a population's general level of mental health. This is in part a result of the increasing life expectancy of those with mental disorders as well as the likelihood that an increased number of people will reach the age at which the risk of such disorders is high. There is a clear association between increased age and risk of developing dementia (Clark & Cummings, 2004; Thomson, Spilsbury, Birks, Barnes, & Adamson, 2007). Helle Wijk (2004) notes that dementia is common in old age, with a 5% prevalence for those in the age group 65 or more. Olivier and Francoise (2005) indicate that the ageing of populations as well as the associated dramatic increase in the frequency of dementia (mental disorders) has become a major public health challenge.

Wimo, Winblad, Aguero-Torres and Von Strauss (2003) report that the worldwide occurrence of dementia in 2000 was estimated at about 25 million persons, and that these numbers are expected to increase significantly. They add that the majority of demented older people live in less developed regions and that this proportion will increase considerably in the future. Mathis, Wang and Klunk (2004) stress that, apart from the huge economic burden that is reflected in the numbers of cognitive impairment amongst older people, an immense emotional burden will be placed upon caregivers whose lives will be severely impacted by their caregiving task.

In the World Alzheimer's Day Bulletin (Prince & Banerjee, 2000), it was predicted that in only 25 years, 34 million people will have dementia. This is due to the increasing life expectancy and ageing of populations in developing countries. Currently, 66% of people with dementia live in developing countries and it is estimated that by the year 2025 this will rise to nearly 75%.

The graph below indicates the projected increase in number of people with dementia for the years 2000 – 2025.

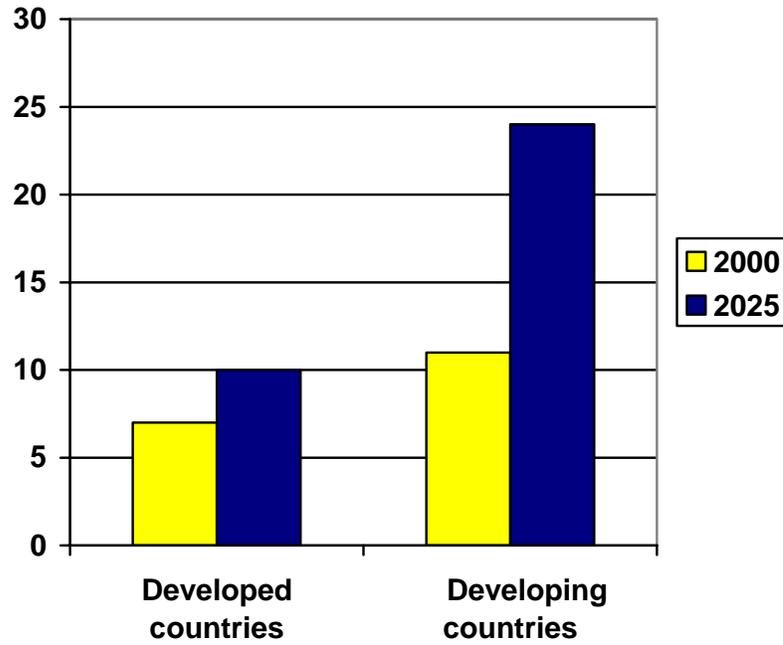


Figure 1. Projected increase in numbers of people with dementia
Total for all countries: 2000 18 million 2025 34 million

1.1 Problem Statement

It is predicted that between 1990 and 2020, there will be an increase of 40% in the age group 75 and above. Health services must provide for this increase to cope with the enormous pressure that this will cause (World Health Organisation [WHO], 2005). Ekwall, Sivberg and Hallberg (2005) point out that, because of demographic changes, more care for older people will be given by informal caregivers who are old themselves. They add that caring for another older person may affect physical and emotional health and could further impact on the quality of life of caregivers.

Alzheimer's Disease International (ADI) indicates that the current figure for dementia patients worldwide exceeds 18 million people, of which about two-thirds (or 12 million) are diagnosed with Alzheimer's disease (AD) (Bosanquet, 2001). These figures are increasing due to the increase in longevity of populations. At the

same time, the number of institutional beds in many countries is reduced, which increases the reliance on home care. Thies (2004) indicates that approximately four million Americans are currently suffering from AD. AD is a disease that affects individuals from every race, sex and all walks of life. It is estimated that at least one in every 10 people over the age of 65 and nearly half of people over the age of 85 are suffering from this debilitating illness. It is further estimated that 22 million people worldwide will develop AD by the year 2025. According to Alzheimers Gauteng Region (personal communication [email], Jean Allen, December 06, 2004), approximately 140 000 people in South Africa are suffering from some form of dementia; and it is expected that this number will increase dramatically as in the rest of the world.

Thies (2004) emphasises that AD impacts on people far beyond those who have it, as AD has a devastating effect on caregivers too. At least 70% of those suffering from AD live at home where family members provide 75% of the needed care. AD caregivers report high levels of emotional and physical stress and are twice as likely as non-caregivers to report physical and mental health complications. It is further estimated that at least one in eight caregivers will become ill or injured as a direct result of caregiving and that at least one in three caregivers uses medication for caregiving-related conditions. Furnish (2002) points out that the specific difficulties of caring for someone with dementia is distinct from any other form of frailty; and that this challenge is not fully appreciated. A study by Beeson (2003) reports high levels of loneliness and depression among caregiving spouses of Alzheimer's Dementia patients (ADps). The study suggested that the mental health needs of AD caregivers should be met by implementing the necessary interventions to assist this group. According to Taylor (2006), as many as one third of primary caregivers of ADps show significant clinical signs of depression. She notes that the care of ADps is enormous and stressful, and suggests that caregivers might need social support to improve their own physiological and psychological functioning.

Bosanquet (2001) confirms that in many Western countries funding changes have left carers of ADps responsible for many of the costs that were previously reimbursed by government, including costs such as medications, hospitalisation and nursing care. These costs could increase the likelihood that these families' economic level falls dramatically in comparison with their contemporaries. Apart from these personal and socioeconomic burdens, the immense intangible

emotional and psychological suffering endured by dementia patients, their carers and families is impossible to quantify. There is an increased recognition that AD is one of the major healthcare challenges of today, and that there are considerable financial, social and emotional costs associated with the care of ADps at home. According to Alzheimer's South Africa (personal communication [email], Jean Allen, December 06, 2004), there is no specific government policy in relation to dementia. Home-based care seems to be the only option as institutional care is limited and not within the financial means of most South Africans.

1.2 Aim of the Research

The absence of meaningful relationships or social contact while caring for a family member can be stressful and lonely. This is especially true for the AD caregiver, who might feel alienated from others (Beeson, Horton-Deutsch, Farran & Neundorfer, 2000). The buffering hypothesis (Taylor, 2006) maintains that the health and mental health benefits of social support are mainly evident during stressful periods. It seems appropriate therefore to propose a research project to address the psychological demands of caring for ADps, especially in terms of social support, given that the lack of such support can adversely affect caregivers and reduce their quality of life (Bell, Araki & Neumann, 2001).

This study was therefore undertaken to ascertain whether there is a lack of social support for caregivers of ADps, and to promote the alleviation of this possible problem through addressing this in caregiver support groups. The study aimed to investigate the social support experienced by ADps caregivers and the effect of social support on the caregiver's life. Emphasis was placed on the effects of this illness on caregivers who are exposed to severely stressful circumstances, with particular attention to the role that social support plays in the caregiver's experience of burden, loneliness and depression; and correlations between social support and loneliness, depression and caregiver burden. The study therefore explores the relationship between loneliness, depression, burden of care and real and/or perceived social support amongst a group of AD caregivers. Caregiver and patient characteristics were included as it is evident from research that these can also play an important role in the caregiver's overall psychological health.

If a lack of social support is experienced amongst caregivers, there is enough research evidence to indicate that this can further escalate into a sense of increased burden and loneliness, which are common contributors to depression. Larrimore (2003) states that “these caregivers live, at best, on a roller coaster existence of emotion and physical activity; at worst, they live lives of quiet desperation”. In a study by Markowitz, Gutterman, Sadik and Papadopoulos (2003), it was found that the burden of caregiving has substantial effects on the caregiver’s quality of health, and that increased caregiver mental functioning was associated with caregiver support, perceived quality of patient medical care, fewer hours of caregiving as well as fewer behavioural problems in the patient. An investigation of the relationship between various psychological components of the caregiving process therefore formed the basis of the investigation, with attention to how changes in one variable correspond with changes in the others.

The motivation behind this aim is in line with the belief that an effort should be made to call for interventions to help ADps caregivers and the broader caregiving community. People whose lives are severely affected by caregiving should be assisted by the community and society at large. Redwood (2002) states that the emotional and social pressure of AD is responsible for a tremendous upset in ageing populations, a situation too serious to ignore. These emotional and social problems have no easy solution; therefore the creation of decision-making structures that integrate medical and social care, drug innovation and caregiving, is urgently needed. An additional motivation is the belief that ADps caregivers should be honoured for the difficult and worthy task that they are performing not only for their loved ones but also for the benefit of the greater society.

1.3 Research Questions

In the absence of meaningful relationships or social contact, caring for a family member can be stressful and lonely. This is especially true for the AD caregiver who might feel alienated from others (Beeson et al., 2000). Chambers, Ryan and Connor (2001, p.100) state that social support is an extremely important part of the coping mechanism as it satisfies the need for “attachment, relieves stress and bolsters a sense of self-worth, trust and life direction”. They discuss a study done in Northern Ireland which found that the majority of family carers felt that they were abandoned and received little emotional support from family, friends and society.

Carers reported that due to the constant demand on their caregiving they were deprived of their social lives, and reported feelings of loneliness and isolation. It is evident that regardless of the huge contribution that carers are making to society, the carers' needs seem to go largely unnoticed, resulting in a general feeling amongst carers that they are not adequately supported.

It is evident that caregivers fear being separated from the world and being left on their own without anybody understanding the enormous change that has taken place in their lives (Morton, 2003). They have to create a new life within the disease where an increased feeling of isolation and loneliness is present. Park (2004) notes that it is widely agreed that a deficiency in an individual's social relationships can result in increased feelings of loneliness, and points out that loneliness correlates positively with depressive symptoms. This author adds that lonely people have other negative life outcomes such as psychosomatic illnesses and a poor self-concept. Redwood (2002) confirms that caregivers, who are often family members and who are usually as old or even older than the patient, face tremendous pressures that may damage their own health unless they receive adequate social and financial support, caregiver training and opportunities for time off.

Based on the literature referred to above, and on the aims of the study, the following research questions were investigated:

- a) What is the relationship between depression, loneliness, burden of care and real and/or perceived social support of carers of Alzheimer's patients?
- b) What is the relationship between psychological health status and ADps caregiver characteristics?
- c) What is the relationship between the psychological health status of ADps caregivers and patient characteristics?

1.4 Chapter Outline

This chapter referred to the far-reaching effects of AD (as the most common form of dementia) on caregivers. Research worldwide indicates that this group is

severely affected by the overwhelming task of caring for AD patients, and that they are vulnerable to a number of negative psychological outcomes associated with the burden of care. This research study aims to explore the relationship between loneliness, depression, burden of care and social support amongst a group of South African AD caregivers. Caregiver and patient characteristics were included in this research study as research indicates that these factors influence both the physical and psychological health outcomes of caregivers. These aims will be implemented as follows:

Chapter 2 provides an introduction to the phenomenon of dementia, and specifically AD. The incidence, stages, clinical profile and aetiology of AD and the caregiver are also discussed.

Chapter 3 explores caregiving in the context of AD and includes a demographic profile of AD caregivers, the psychological impact of caring for ADps, burden of care as well as stress and coping.

Chapter 4 contains an in-depth discussion on social support and the caregiving process. The chapter explores different types of social support, the relationship between social support and psychological health status, theories, benefits and therapeutic effects of social support for the AD caregiver.

Chapter 5 explains the methodology of the study, and includes the research design, aims of study and research questions, sampling procedures, ethical considerations, measuring instruments, data collection and analysis.

In **Chapter 6** the results of the statistical analysis are interpreted by means of descriptive studies, correlations and regressions, and consist of the following:

- biographical information of caregivers and patients
- Beck's Depression Scale
- The Memory and Behaviour Problem Checklist and the Burden Interview
- UCLA Loneliness Scale
- Personal Resource Questionnaire PRQ85: part 1, which consists of a Personal Resource Questionnaire; and part 2, which measures perceived social support

Chapter 7 concludes the study with an explanation of caregiving in the context of AD, including the variables of loneliness, depression, burden of care and social support. The research findings are discussed and compared with the literature. Reflections on caregiving and intervention strategies for AD caregivers, limitations of this study as well as recommendations are also discussed in this chapter.

CHAPTER 2

ALZHEIMER'S DEMENTIA

Mathis, Wang and Klunk (2004) see the biggest challenge of the 21st century as the ageing of society: while people enjoy increased longevity, there is a concomitant increase in ageing-related neurodegenerative disorders. According to Furnish (2002), dementia is a syndrome caused by disease of the brain, which is usually chronic and of a progressive nature. The disturbance that occurs is of the higher cortical functions that include memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The cognitive function impairment can accompany and sometimes precede deterioration in emotional control, social behaviour or motivation. This is confirmed by Desai, Grossberg and Sheth (2004), who describe dementia as a syndrome of progressive decline that leads to the erosion of intellectual abilities, causing cognitive and functional deterioration which furthermore result in the impairment of social and occupational functioning. All dementias can be defined in terms of the functional disability that is its main feature. Howcroft (2004) states that dementia is a syndrome that is associated with older people. AD is the most common form of dementia, and accounts for at least 50% of cases.

2.1 Definition of Dementia

The term *dementia* refers to a family of diseases that involves cognitive and behavioural deficits that also include permanent brain damage. Approximately a dozen forms of dementias have been identified. Dementia involves identifiable damage to the brain that causes severe cognitive and behavioural decline that is not caused by a rapid onset of a toxic substance or by infection. Dementias such as AD and Parkinson's disease, Pick's disease, Creutzfeldt-Jakob disease, Huntington's disease, normal-pressure hydrocephalus and alcoholic dementia are irreversible and degenerative (Cavanaugh, 1997). According to Larner (2005) and O'Leary, Jyringi and Sedler (2005), other forms of dementia include vascular dementia or vascular cognitive impairment, dementia with Lewy bodies, alcohol-

related dementia as well as multi-infarct dementia. Fisher, Yury and Buchanan (2006) indicate that the most common forms of degenerative dementia are AD and vascular dementia, while Lewy body disease and frontotemporal forms of dementia follow as the next most common forms of irreversible dementia. Reversible conditions that can cause symptoms of dementia include infection, high fever, drug reactions, dehydration, vitamin deficiency poor nutrition, head injury and normal pressure hydrocephalus (Fisher et al., 2006).

According to Cavanaugh (1997), dementias can be classified in several ways. For many years the age of onset of the illness was used for classification. Dementias diagnosed in people younger than 60 to 65 were termed pre-senile and those diagnosed in people older than 60 to 65 termed senile dementia. However, this terminology changed in popularity and meaning due to new discoveries and the fact that age has little to do with the types of underlying neurological changes. Clark and Cummings (2004) found, however, that AD is the most common form of late-onset dementia.

2.1.1 Incidence of dementia

Graham (1999) indicates that due to the inevitable ageing of populations a dramatic increase in the number of people with dementia in the next 25 years is predicted. According to Yap, Seow, Henderson and Goh (2005), the most recent estimates indicate that 24,3 million people worldwide suffer from one or other form of dementia. Furnish (2002) compares the 1994 estimate that there were 70 million people in the age group 60 and older in the European Union with the prediction that this figure will increase to 113,5 million by the year 2025. This is an indication that between a quarter and one third of the total population could be elderly. The vast increase within the older population occurred in Western societies specifically in the age group of 75 years and older, and is a trend that is likely to continue. For example, the predicted growth in the population age over 80 is 18% in Sweden and 21% in the UK. The increase in the proportion of much older people in the average population group can be a significant forecaster of the demand for future dementia services, as a rapid increase in dementia is experienced in the age group beyond 60 years.

Wimo et al. (2003) stress that while the number of people with dementia in 2000 was estimated at about 25 million people worldwide, almost half (46%) of the

demented persons lived in Asia, 30% in Europe, and 12% in North America, with 52% of these people living in less developed regions. In the population group of 65 years and older approximately 6,1% suffered from dementia, which is more or less 0,5% of the worldwide population, and approximately 59% of sufferers were female. These authors predicted that a considerable increase in the number of older people with a form of dementia will occur: from 25 million in the year 2000 to 63 million in 2030. Furthermore it is expected that 41 million of these patients will live in less developed regions. An overall increase of 114 million older dementia patients is expected in 2050, of which approximately 84 million will be living in less developed regions. Graham (1999) agrees that while presently most people with dementia live in developed countries, it is anticipated that by 2025 at least 70% of people with dementia will hail from developing countries. Clark and Cummings (2004) confirm that while the older segments of populations are rapidly growing all over the world, a simultaneous increase in the incidence of dementia is expected, with a projected total of at least 8,64 million cases by the year 2050.

According to Mok, Chu, Chung, Chan and Hui (2004), the incidence of dementia in Hong Kong alone is 6,1% for people 70 years and older, with an increase every five years for patients over the age of 70. According to Alzheimer's South Africa (2004), there are approximately 140 000 people in South Africa with some form of dementia; and as in the rest of the developing world a dramatic increase in these figures is expected.

2.2 Definition of Alzheimer's Disease

Hoyer and Roodin (2003) refer to AD as a degenerative brain disease associated mostly with cognitive failure in older adulthood, in which the person loses abilities such as memory, recognition and reasoning. In 1907 the German neurologist Alois Alzheimer first identified neuritic plaques (NPs) and neurofibrillary tangles (NFTs) in the postmortem brain tissue of a patient with dementia. The result was that NPs and NFTs in the postmortem brain have become the two pathological hallmarks that are characteristic of AD, and provide the basis for a definite diagnosis of AD (Holmes, 2006). It was found that in AD, plaques and tangles are highly concentrated in brain regions of high neuronal cell loss such as the associative cortex and hippocampus (Mathis et al., 2004).

Rubin (2005) adds that apart from the multifaceted loss of intellectual abilities and other higher cortical functions in patients with this progressive dementia, changes in personality and behaviour may also occur. Cavanaugh (1997) lists additional major symptoms as being the gradual and pervasive loss of memory, emotional changes, and eventually the loss of motor functions. Hoyer and Roodin (2003) refer to AD as the most devastating age-related brain disorder whose primary symptom is the abnormal deterioration of mental functioning which is not part of the normal ageing process.

Barrett (2005) believes that although AD could be an obvious diagnosis in patients with a classical combination of gradual, early memory loss and cognitive problems in multiple domains without attention disorder or delirium, other treatable conditions can mimic this stereotyped pattern. Conditions such as depression, stroke, Parkinson's disease, vitamin B₁₂ deficiency, thyroid disorders, thiamine deficiency, primary gastrointestinal disorders, structural brain lesions, cancer and neurosyphilis can be mistaken for AD. This is confirmed by Cavanaugh (1997), who advises that all other possible systemic disorders and brain diseases that could cause progressive deficits in memory and cognitions should be eliminated. Thus the diagnosis of AD requires ruling out all other possible causes of the symptoms and involves thorough physical and neurological tests.

AD is a progressive and fatal disease, which can only be definitely diagnosed by an autopsy that shows the occurrence of three neurological changes, namely, NFTs, NPs and granulovacuolar bodies. Therefore, the diagnosis of AD is made on the basis of the clinical criteria of AD as well as histopathological evidence obtained via autopsy, and in some instances, a biopsy; although this is rarely used (Cavanaugh, 1997; Holmes, 2006). Lachs and Boyer (2001) cite studies indicating that the diagnosis of AD by experienced physicians and geriatricians is confirmed by autopsy in 95% of instances.

According to Desai et al. (2004), the DSM-IV diagnosis of AD requires the identification of cognitive deficits that are severe enough to cause impairment in both occupational and social functioning, and that patients show a decline in a previously higher level of functioning. The DSM-IV criteria for dementia include the following (Clark & Cummings, 2004):

- short- and long-term memory impairment

- impairment in abstract thinking, judgement, other higher cortical function or personality change
- cognitive disturbance that interferes significantly with work, social activities or relationships with others
- these cognitive changes do not occur exclusively in the setting of delirium

Clark and Cummings (2004) further list the NINCDS-ADRDA criteria for the diagnosis of AD as follows:

Probable AD: Core diagnostic features

- (a) Dementia established by clinical examination (including Mini-Mental Status Exam (MMSE), Blessed Dementia Rating Scale (BDRS), and neuropsychological testing)
- (b) Deficit in at least two areas of cognition
 - (i) memory (required)
 - (ii) other area besides memory
- (c) Deficits characterised by gradual onset and progression, onset after age 40
- (d) Other systemic disorders or brain disease do not account for the progressive deficits in memory and cognition in and of themselves

Possible AD: Core diagnostic features

- (a) Dementia syndrome in the absence of other neurologic, psychiatric, or systemic disorder, OR
- (b) Presence of a second systemic or brain disorder sufficient to produce dementia, which is not considered to be the primary cause of the dementia

Features that make a diagnosis of probable or possible AD unlikely or uncertain

- (a) Sudden apoplectic onset
- (b) Focal neurologic findings such as hemiparesis, sensory loss, visual field deficits and incoordination early in the course of the illness.

Criteria for diagnosis of definite AD

- (a) Clinical criteria for probable AD
- (b) Histopathologic evidence obtained from a biopsy or autopsy

2.2.1 Incidence of Alzheimer's disease

According to Mathis et al. (2004), AD is one of the most common cognitive impairment disorders found among older people. In industrialised societies the incidence of AD is exceeded only by heart disease, cancer and stroke, making it the fourth leading cause of death.

2.2.1.1 Alzheimer's disease and age

The possibility of contracting AD increases with age, and research indicates that current estimated rates for cognitive impairment across Europe could be as high as 4,5% in men and 6.5% in women over 60 years, with an increase to 32% in men and 34% in women over the age of 90 years (Furnish, 2002). Howcroft (2004) states that AD is the most common form of dementia, and is a syndrome that is specifically associated with older people. The Alzheimer's Society estimates that there are approximately 18,500 people in the UK under the age of 65 years who have dementia (Howcroft, 2004). The risk of developing dementia increases with age and could be as high as one in five at age 80 years and above. AD accounts for at least 50 percent of cases of dementia. It is further estimated that as many as 1,5 million people in the UK alone might be caring for a relative or loved one with some or other form of mental illness such as dementia.

2.2.1.2 Alzheimer's disease and longevity

The average life expectancy in the developed world has increased and it is estimated that by the year 2025 the life expectancy of the average person will be around 100 years of age (Lund, 2001). Mathis et al. (2004) report that against the background of increased incidence of AD as a result of population ageing, it is estimated that by the year 2050 there will be 14 million cases of AD in the USA alone. Alzheimer's South Africa (2006) stress that South African statistics on the prevalence of AD are not available due to the challenges facing epidemiological research in South Africa.

Ferreira and Makoni (2000) believe that the number of older people will double in only 17 years, and Africa is no exception. The government of South Africa as well as healthcare systems will encounter tremendous pressure to provide for the needs of the growing population of older people. Demographic changes will also mean that there will be an inevitable increase in age-related diseases, including dementias such as AD. There will thus be an increased demand for caregiving. As

AD progresses, increased assistance from health and social services will be needed to enable carers to continue with the caregiving process (Howcroft, 2004).

2.2.2 Stages of dementia

According to Howcroft (2004), the stages in which the dementia develops are as follows :

2.2.2.1 Questionable dementia

Questionable dementia is when a mild form of forgetfulness is experienced without orientational problems. Other symptoms in the earlier stages of the illness may include difficulty in problem solving as well a decrease in general interest within and outside the home environment. However, the person remains independent in terms of self-care.

2.2.2.2 Mild dementia

During *mild dementia* there is a moderate loss in recent memory that has an effect on daily living, as well as some disorientation in time, place and in unfamiliar surroundings. During this phase patients also experience difficulty in handling complex problems, and struggle to maintain interest outside the home environment. They may abandon complicated tasks at home and may require assistance with self-care.

2.2.2.3 Moderate dementia

With *moderate dementia* a severe memory loss is experienced and only highly learned material can be retained. Patients are disoriented to time and place and struggle to solve problems and make judgements. Patients are unable to function independently away from home and are able to do only the simplest chores while assistance is needed in areas such as hygiene and dressing.

2.2.2.4 Severe dementia

During the stage of *severe dementia* the memory loss becomes severe, with fragmented mental activity and complete disorientation, although a sense of own identity remains intact. The person becomes totally dependent and cannot function outside the home environment, cannot solve any problems or make judgements, and often becomes incontinent.

2.3 Clinical Profile of Alzheimer's Disease

2.3.1 Neuroanatomical changes

Goldberg (2005) stresses the complexity of the pathophysiology of AD that makes it a complicated illness to address. According to Cassimjee (2004), Alzheimer's disease is distinguished from the normal processes of ageing on a neuropathological as well as a cognitive level, and is characterised by cytoskeletal mutations such as tangles and plaques as well as neurochemical imbalances. Holmes (2006) notes that AD is characterised at a microscopic level by the presence of large numbers of NPs and NFTs.

Alzheimer's disease is characterised by microscopic changes in the brain. This means that a definite diagnosis can only be made by means of an autopsy. These microscopic changes include neurofibrillary tangles, neuritic plaques and granulovacuolar degeneration (Cavanaugh, 1997). AD plaques and tangles are highly concentrated in brain regions of high neuronal cell loss such as the associative cortex and hippocampus (Daselaar, Fleck, Dobbins, Madden & Cabeza, 2006). The progressive changes that occur in the brain cause so much destruction that the person eventually dies.

2.3.2 Neurochemical changes

Hoyer and Roodin (2003) identify the cholinergic hypothesis as one of the most influential theories on AD. The cholinergic hypothesis proposes that AD is caused by decrements of the neurotransmitter acetylcholine, which could explain why the neurons in the hippocampus and temporal lobe are among the most negatively affected parts of the brain in AD patients. This theory also explains the cognitive symptoms associated with AD. Daselaar et al. (2006) indicate that both the hippocampus and rhinal cortex are impaired in AD. According to Cavanaugh (1997), AD causes irreversible changes in the nerve cells of certain vulnerable areas in the brain. Nerve cell loss, abnormal tangles with nerve cells and deficiencies of several chemicals, which are essential for the transmission of nerve messages which are typical characteristics of AD.

2.3.3 Histopathologic changes

Yoshimura, Isotani, Yagyū, Irisawa, Yoshida and Sugiyama (2004) emphasise the histopathological changes that occur in AD. These authors discuss

electroencephalography (EEG) as one of the best diagnostic approaches as it is completely noninvasive, has a good cost/benefit ratio and offers virtually unlimited time resolution. There is consensus that the earliest EEG changes in AD include an increase in theta activity, which is accompanied by a decrease in beta activity, followed by a decrease in alpha activity. As the illness advances delta frequency increases. It is further suspected that the higher EEG complexity of mild AD implies a decline in the harmony of brain activity due to histopathological changes in the brain. Bondareff (1996) indicates that research into the histopathologic underpinnings of psychotic symptoms in AD has yielded valuable results. The accumulation of Paired Helical Filament (PHF)-Tau protein in neurons and the effect it has on neuronal metabolism has particular significance, as once a neuron is filled with this abnormal protein, it cannot be salvaged. Hasagawa (2004) identified neurofibrillary tangles as being a bundle of abnormal paired helical filaments of which the main component is hyperphosphorylated tau protein. If intervention could take place in the early stage when PHF-tau is just beginning to form in cells, it may be possible to treat psychotic symptoms in AD patients.

2.3.4 Neuropsychological changes

The National Institute of Neurological and Communicate Disorders and Strokes – Alzheimer’s Disease and Related Dementias Association (NINCDS-ADRDA) Work Group believes that the assessment of functional performance should be an important component of a comprehensive diagnostic evaluation for AD (Desai et al., 2004). Functional status refers to the performance of everyday activities in the home and community. Two major types of abilities associated with functional impairment in dementia are basic activities of daily living (BADL) and instrumental activities of daily living (IADL). BADL include skills that are needed for self-maintenance such as dressing, bathing, toileting, grooming, eating and ambulating. IADL are associated with more complex, higher order skills such as driving a car, taking medications, shopping, working in an occupation, managing finances and using the telephone. In general, problems associated with AD usually start first in the execution of IADL, progressing to a stage where even less complex BADL functions of personal care are ceased. Difficulty in performing the more complex IADL tasks might be the family’s first indication of the earlier stages of the disease. In the later stages of the disease the patient may become totally dependent on caregivers. IADL could assist clinicians in diagnosing AD in the earlier stages of the disease while BADL could be used as a tool to increase the specificity and sensitivity of the diagnosis of dementia. Włodarczyk, Brodaty and Hawthorne

(2004) stress that IADL measures the capacity to perform everyday life tasks, and point out that caregiver psychological well-being correlates with IADL. Arai, Sugiura, Miura, Washio and Kuo (2000) found that caregivers who look after older people with severe dependency in ADL (activities of daily living) were three times more likely to use public services than those who did not.

2.3.4.1 Cognitive and behavioural symptoms

Fernandez-Ballesteros (2003) indicates that AD can progress over many years with increasing cognitive impairment resulting in the escalation of behavioural problems. Cavanaugh (1997) adds that AD is characterised by a gradual change in the cognitive functions that govern word-finding ability and communication. Behavioural symptoms include a decline in the person's hygiene, self-care skills as well as inappropriate behaviour. Robinson and Plosker (2006) note that the progressive and irreversible loss of neurons in regions of the brain is responsible for cognitive decline that could involve functions such as language, judgement, decision making, orientation, learning and memory.

2.3.4.2 Personality changes

Research indicates that personality changes often occur early in AD, even before a formal clinical diagnosis is made (Balsis, Carpenter & Storandt, 2005). This has major implications as personality changes could be an aid in detecting AD at an early stage, enabling early treatment of the disease. Balsis et al. (2005) believe that personality-related change could be an early symptom of AD and might be present even before cognitive decline takes place. According to Welleford, Harkins and Taylor (1995), Alois Alzheimer listed personality-related change as an early symptom of AD. Cavanaugh (1997) indicates that AD is not only characterised by a gradual decline of cognitive functions, personal hygiene, self-care skills, and inappropriate behaviour on a social level, but that there is also enough evidence to suggest that personality changes takes place.

2.3.4.3 Psychiatric symptoms

Hoyer and Roodin (2003) indicate that in the end stages of AD the afflicted person develops extensive physical as well as mental disabilities that commonly result in institutionalisation. Cavanaugh (1997) points out that depression, irritability, wandering and emotional problems are all factors to be dealt with in, making AD a very complex illness. Apart from impairment in functions that involve higher level cortical integration (including general intellect, planning, organisation, reasoning,

orientation, speech, mathematical skill, and so on), psychotic symptoms including delusions and hallucinations may also appear (Rubin, 2005).

2.4 Theories of aetiology

Although according to Hoyer and Roodin (2003) there is no single identifiable cause of AD, a number of different theories may account for the development of AD. These theories are briefly discussed in this section.

2.4.1 ApoE genotype

The apolipoprotein E (ApoE) gene has been identified as a major risk factor in the process of AD by accelerating the decline of the glucose metabolism in the brain that has been associated with AD (Masconi et al., 2004). Raber, Huang and Ashford (2004) propose that the three major human isoforms, ApoE2, ApoE3 and ApoE4 are encoded by different alleles (epsilon 2, epsilon 3, epsilon 4) and are responsible for the regulation of the lipid metabolism and the redistribution thereof. Indications from clinical and epidemiological data suggest that the epsilon 4 allele may account for 50% of AD occurrences in the United States. It is further indicated that fragments of ApoE may contribute to the formation of both plaque and tangles. It is thus suggested that the ApoE genotype accounts for a large portion of the risk for AD and pathology (Raber et al., 2004).

2.4.2 Genetic hypothesis

According to Hoyer and Roodin (2003), the *genetic hypothesis* of AD is based on the discovery that early-onset familial AD (FAD) runs in families and that FAD is associated with a defective gene located on chromosome 21. It was further found that the gene that is responsible for the production of amyloid (which is the core material of senile plaques) is also located on chromosome 21. There is evidence that most individuals who have Down's syndrome (which is related to extra-chromosomal material on the 21st pair) develop AD symptoms from about age 40. It seems therefore that in both AD and Down's syndrome patients, the amyloid deposits in the brain and the accumulation of senile plaques may have the same origin, namely, chromosome 21. It is also known that a mutation in a gene on chromosome 21 is responsible for encoding an amyloid precursor protein (APP), which is the chemical substance responsible for the manufacture of amyloid. However, the genes that are responsible for the production of APP and Down's

syndrome are positioned in very different locations on chromosome 21, which makes it difficult to fully understand the relationship between AD, amyloid production and Down's syndrome. Redwood (2002) notes that risk factors for AD include old age, Down's syndrome, a family history of dementia and an APOE genotype.

2.4.3 Cholinergic hypothesis

Hoyer and Roodin (2003) indicate that one of the influential theories is the *cholinergic hypothesis*, which suggests that AD is caused by decrements in the neurotransmitter acetylcholine. This theory stems from findings that the neurons in the hippocampus and temporal lobe of AD patients are amongst the most negatively affected parts of the brain. These brain structures employ acetylcholine as their primary neurotransmitter. In AD patients, the basal forebrain neurons that manufacture acetylcholine are substantially reduced; the brains of AD patients contain significantly less acetylcholine than those of unaffected individuals. Although this theory has generated a great deal of important research, it lacks clarity on whether the reduction in acetylcholine is a cause or an outcome of AD. However, Cassimjee (2004) notes that while the cholinergic effects impact on the cognition (memory), the neuropsychiatric and behavioural aspects of the illness are influenced by the other neurotransmitters.

2.5 Alzheimer's Disease and the Caregiver

Tebb and Jivanjee (2004) confirm that AD is the most common form of irreversible dementia, and because it is a progressive illness, the level of care needed increases with time. Mohamed (2000) stresses that, besides the fact that Alzheimer's is recognised as the most severe form of intellectual impairment of older people, it also has the most devastating effect on the person's family. Furthermore, according to Fernandez-Ballesteros (2003), evidence suggests that behavioural problems are more difficult to manage than physical impairment, and over time escalate into a far greater burden. This is likely to be especially true for AD patients as the illness can progress over many years with increased cognitive impairment, resulting in the escalation of behavioural problems. Desai et al. (2004) suggest that treatment that could preserve or slow down the rate of decline of functional abilities in a patient with AD could also reduce caregiver burden.

2.5.1 Increased care and supervision

Alzheimer's disease (AD) patients live an average of eight years, and in some instances can survive for 20 years or more from the onset of the symptoms – with devastating effects on caregivers (Thies, 2004). According to Murray and McDaid (2002), as the dementia progresses the patient requires increased care and supervision due to the simultaneous deterioration of both physical and mental capacity. This is a tremendous challenge to caregivers (Furnish, 2002). Tebb and Jivanjee (2004) add that as the demands of caregiving increase, caregivers sometimes have to give up their employment, social lives and all activities that might bring them in touch with other people. As AD progresses, couples lose the companionship that they previously enjoyed. Furthermore, with the demands of daily caregiving, caregivers might even neglect their own physical health. Social isolation is unfortunately a common outcome of prolonged caregiving.

2.5.2 The caregiver and emotional and physical stress

According to Thies (2004), high levels of emotional and physical stress are experienced by caregivers of ADps, and when compared to con-caregivers, they are twice as likely to report physical and mental health complications. There is further evidence that at least one in eight caregivers will become the victim of an injury as a direct result of caregiving, while one in three caregivers uses medication for caregiving-related problems. Depression amongst caregivers is three times that of other people in the same age group. Tebb and Jivanjee (2004) note that the cognitive and physical decline of the ADp affects caregivers' physical and psychological health as well as their social and economic well-being. Studies of ADp caregivers show that severe and long-term stressors, such as those that result from caregiving (and specifically caring for older people) may leave caregivers vulnerable to a range of health-related problems that can persist well beyond the end of the stressful situation (Taylor, 2006).

2.5.3 The caregiver and the burden of care

As AD progresses, ADps require increasingly more assistance with activities of daily living (McClendon, Smyth & Neundorfer, 2004). Thies (2004) states that in the later stages of the illness, ADps require 24-hour supervision that could include assistance with eating, grooming and toileting. The ADp eventually becomes totally dependent on the caregiver, with the result that the caregiver may become physically and emotionally exhausted. The extended period of caregiving (which

may last up to 20 years), the total dependency of the patient, and the need for 24-hour supervision contribute to high levels of emotional and physical stress among caregivers. On a different level, the diagnosis of Alzheimer's shatters caregivers' dreams and plans for retirement, leaving their lives and future plans in disarray (Tebb & Jivanjee, 2004; Ekwall & Hallberg, 2007).

2.6 Conclusion

This chapter explored how the increased longevity of the human population increases the risk of dementia, of which AD is the most common form. Families caring for AD patients carry a great burden emotionally, physically and financially. Research is needed to enable the relevant role players to understand and provide assistance to this very vulnerable group. Clyburn, Stones, Hadjistavropoulos and Tuokko (2000) found that high frequencies of disturbing behaviour by ADps, caring for an indwelling patient, and low levels of informal support were all related to higher burden experienced by ADp caregivers. This in turn led to increased depressive symptomatology in the caregiver. These authors recommended that intervention programmes be designed to assist caregivers in the management of disturbing behaviours, provide them with better formal support and improve their coping skills.

In the following chapter the process of caregiving in the context of AD is discussed in detail.

CHAPTER 3

CAREGIVING IN THE CONTEXT OF ALZHEIMER'S DISEASE

3.1 Caregiving

Biegel and Blum (2001) indicate that during the past decade there has been an increase in awareness of the significant role that families play in providing care for dependent family members. The provision of care by informal service providers has been the dominant source of health care to most needy individuals. According to Gwyther (1998), it is evident that the burden of care of severely cognitively impaired older people is carried mostly by informal carers, even more so than with physically frail older people who have a similar degree of disability. Coping with a degenerative brain disease is different from and more complex than dealing with a physical disability, for instance. The availability of informal carers, who are usually relatives, is therefore of crucial importance in providing services to people with a degenerative brain disease (Furnish, 2002).

According to Yap et al. (2005), caregiving can be understood as the provision of extraordinary care, and may stretch over a lengthy period. Caregiving often also entails significant investment of time, energy, and finances; often involves unpleasant tasks, and may be emotionally and physically stressful. Fernandez-Ballesteros (2003) explains the evolution of the caregiving process according to the following hypotheses:

- (1) the *wear-and-tear hypothesis* suggests that as the illness progresses, a decrement in the caregiving functioning is unavoidable;
- (2) the *adaptation hypothesis* proposes that caregivers eventually adapt to the demands of the caregiving situation so that their caregiving may even improve;
- (3) depending on the caregivers' coping skills and social support, the *trait hypothesis* suggests that caregivers maintain a constant level of functioning; and
- (4) the *glucocorticoid cascade hypothesis* states that immune functioning in older people can be severely and persistently affected by chronic stressors.

3.1.1 Caregiving and the Alzheimer's disease patient

AD results in the progressive decline of cognitive functions as well as people's ability to perform normal daily tasks (Wlodarczyk et al., 2004). As AD progresses, patients require increased care and supervision due to the simultaneous deterioration of both physical and mental capacity (Murray & McDaid, 2002). Thies (2004) warns that caregiving inevitably becomes a 24-hour task, which includes assistance with daily activities such as eating, grooming and toileting, with patients eventually becoming totally dependent on the caregiver.

Wlodarczyk et al. (2004) emphasise that the disease not only affects the patient's overall health-related quality of life but also that of the primary caregiver. The ADp's caregiver's responsibilities are much more complex and extensive than is evident from the visible duties they perform. According to Thies (2004), at least 70% of Alzheimer patients are taken care of at home where their families provide 75% of the care needed. Biegel and Blum (2001) point out that, if this network were not available, professional institutions would be inundated with demands for service that they would not be able to render.

Due to prolonged nature of the illness, as well as the fact that the patient becomes totally dependent on the caregiver, caregiving becomes an increasingly exhausting task (Thies, 2004).

3.1.1.1 Factors associated with burden of care

Murray and McDaid (2002) refer to the long-term costs and effects upon morale as carer burden. In the Eurocare study that was conducted in 14 countries, there were no differences in carers' reports, with each sample describing the same range of difficulties with similar frequencies. One of the most important findings in this study was a highly statistically significant association between patient behavioural disturbance and the increased burden experienced by the caregiver. Another important finding was the consistently high ratings of carer burden and carer psychological distress across the countries of the EU. Murray, Schneider, Banerjee and Mann (1999) note that recognition of the role of family caregivers, as well as the support from statutory authorities, seems to be low in most countries. A study that involved caregivers who were co-resident spouses of persons diagnosed with AD revealed increased workload, reduced emotional support and social isolation as the biggest burden (Murray et al., 1999). According to Howcroft (2004),

the predictors of caregiver burden are a lack of social support as well as increased behavioural problems of the ADp.

Chambers et al. (2001) conducted interviews with two focus groups comprised of seven family caregivers each to explore the emotional support needs and coping strategies of family carers. The purpose was to investigate family carers' needs and experiences, with specific attention to the emotional support needs and coping strategies identified by group members. The issues discussed included information and social support needs, the emotional impact of caregiving as well as adapting to the caregiving role. The findings reveal that most family caregivers searched constantly for support and information. They experienced anxiety and frustration with the lack of information, and the inconsistent and irregular support they received. Cavanaugh (1997) indicates that drastic alterations in habits, such as the change in a carer's entire daily routine, as well as observing the deterioration of a loved one, is extremely difficult and stressful for the caregiver. Apart from the fact that caring for a person with dementia can be very stressful and time-consuming for many caregivers, it eventually becomes a full-time job. Caregivers move from a lifestyle where they experience control over situations to one that totally controls them. Other negative effects of caregiving include chronic fatigue, loss of friendships, anger and depression, loss of free time, and physical and mental strain. Dissatisfaction with other family members is also a factor that should be recognised, and which may contribute to a further decrease in life satisfaction and well-being. Gwyther (1998) states that families of AD patients must make ever-increasing adjustments and adaptations, which often occur in the context of uncharacteristic resistance, indifference or suspicion from a relative with impaired judgement and memory. Common issues that are confronted by these families include isolation, unpredictability, fear, fatigue, and overwhelming loss of control. Gwyther (1998) states that studies have shown that personality and behavioural changes in AD patients are directly correlated to caregiver feelings of burden.

In a study by Jansson, Nordberg and Grafström (2001) about patterns of elderly spousal caregiving in dementia, it was found that unimpaired spouses were transformed from equal partners to caregivers and were caring "for" as well as "about" their spouses. According to Bosanquet (2001), carers suffer from stress, sleeplessness, fatigue, anxiety, depression. This author reports that impaired immunological response is found amongst carers, whose use of psychotropic drug assistance from the healthcare system increases. The burden often becomes too

much, and the ADp is often eventually placed in a long-term care facility. Jansson et al. (2001) conclude that, apart from the instrumental and invisible care, other visible aspects of caregiving such as the physical presence of the caregiver (on which the impaired person is dependent), the repetitive conversation, guidance with activities as well as necessary reminders, increased the burden experienced by the caregiver.

3.2 The Demographic Profile of the Alzheimer's Disease Caregiver

Fernandez-Ballesteros (2003) states that the growing number of older people has foregrounded the issue of caregiving, and highlighted the change in family patterns where it was traditionally assumed that women would take on the caregiving role. Olivier and Francoise (2005) agree that the swell in older populations, accompanied by a dramatic increase in dementia, has become a major public health challenge. Yap et al. (2006) confirm the alarming statistics of dementia worldwide, and state that family carers remain the main source of care for the cognitively impaired. Ekwall, Sivberg and Hallberg (2005) add that demographic changes mean that caregiving by older people, who may be in poor health themselves, will increasingly become a reality.

3.2.1 Older people as caregivers

Fernandez-Ballesteros (2003) indicates that the role of caregivers has been extensively studied since the 1980s due to the growing number of older people and the changing patterns of families. Moreover, the traditional role of caregiver was given to women. The average profile of a caregiver at risk is a middle-aged or older woman who lives with the patient. Although caregiving is not limited to any one person (anyone can become a caregiver), in general caregivers tend to be women of approximately 57 years of age. Fernandez-Ballesteros (2003) reports that spouse caregivers tend to be in their late 60s and 70s, and when compared to the general population, statistics show that more caregivers are unemployed, poor or close to poverty, and in fair to poor health. Usually women are the sole care provider, who experience health problems with limited personal, social or financial resources. Caregivers usually have social or job-related obligations that compete directly with their caregiving demands. They have typically experienced previous problems in their relationship with the patient, and experience the caregiving role as a major disruption to their personal life.

Due to demographic, economic and social changes, the caregiving needs of older people have come to the fore. This explains the increased research interest in practice and policy issues of family caregiving. Life expectancy has increased drastically over the last century, and together with other demographic and social trends, has resulted in a dramatic increase in the older population (Biegel & Blum, 2001). Cavanaugh (1997) states that the current significant increase in the number of older people, as well as future predicted increases, clearly indicate that the ageing of populations should be factored into social policy. Cavanaugh predicts that the change in demographics will have an enormous effect on all aspects of life in the United States as well as on all health care and all social services programmes. This is a trend that may be expected throughout the rest of the world.

Jansson et al. (2001) emphasise that the increase in the number of older people challenges social policies in countries such as Sweden and many industrialised countries. An increase in the proportion of people over 80 years means higher levels of dependency, and a simultaneous increase in older carers. Redwood (2002) confirms that caregivers are usually family members who are old themselves, and that the pressure of caregiving erodes their own health unless they receive social and financial support as well as training and other opportunities for relief from caregiving duties.

Jansson et al. (2001) indicates that informal care rendered within the family is more or less invisible, although caregivers sacrifice most of their own lives to take care of the impaired spouse. In light of this, spouses who are willing and capable of caring for their partners should be given the best resources possible. Burns (2000) agrees that informal caregivers play a crucial role in the care of ADps, and adds that family carers experience extreme hardship and distress that is often not acknowledged by the healthcare system.

According to Cavanaugh (1997), higher levels of morale are reported amongst caregiving men than women. This may be because women are more emotionally involved in the caregiving role, and because they tend to care for more severely impaired patients. Lower levels of physical health, mental health and financial resources are reported by spouses who care for their partner in comparison to spouses who do not have this burden. In a study undertaken with 242 husbands, wives and daughters who provided care for AD family members, Beeson et al.

(2000) report significant differences between the female and male participants. Caregiving wives and daughters reported higher means scores compared to caregiving husbands on items such as relational deprivation, loneliness and depression. In another study by Ferrario, Vitaliano, Zotti, Galante and Fornara (2003), spouse caregivers reported greater perceived burden than child caregivers, which the researchers contributed to the fact that child caregivers were most probably still working outside the home. Other reasons for this finding are that the most important affective reference for spouse caregivers is the patient, whereas child caregivers have other people as their familial and affective points of reference.

It is well recognised that older people are a marginalised group with decreasing physical capabilities and increased economic disempowerment (Hoyer & Roodin, 2003). Because older people live on fixed incomes, escalating health care costs become an increasing burden. Successful ageing is also related to being able to maintain a social network. This in itself can be very problematic for the caregiver of the ADp. Furthermore, according to Gwyther (1998), a great number of older people over the age of 85 live with a chronic illness themselves while caring for an AD patient. Jansson et al. (2001) support this by stating that many caregivers themselves are old and sometimes in poor health; and state that they must thus be protected from becoming patients themselves.

3.3 Psychological impact of caregiving

AD is arguably more disruptive and has a greater impact on the family than any other chronic disease (Gwyther, 1998; Mohamed, 2000). In a study by Vetter et al. (1999) that compared vascular dementia (VD) with dementia of the Alzheimer's type (AD) and examined the effect of each on caregiver burden, it was found that in the earlier stages, VD patients imposed a greater burden on the caregiver than AD patients. In more severe stages this relationship is reversed. Fernandez-Ballesteros (2003) suggests that the behavioural problems associated with AD are more difficult to manage and result in increased burden over time. He further indicates that while physical stress occurs from assisting the patient with ADLs, the psychological and social costs associated with the caregiving process are far more difficult to measure.

Despite their best efforts in providing long-term care around the clock, caregivers can become victims of physical and emotional exhaustion. The impact of Alzheimer's disease should not be expressed only in terms of the number of people affected or the cost of their care, but also in terms of the devastating psychosocial effect that creates unique and problematic issues for both family caregivers as well as healthcare and social services. The caregiver becomes the second victim of the illness because of the extended period of grieving that the caregiver(s) experience, the total dependency of the patient, the 24-hour supervision required from caregiver, the enormous financial burden with little or no relief from public sources or private insurance, and the withdrawal of support systems as the illness progresses. Caregivers may become so exhausted emotionally, physically and financially that they cease their caring activities (Scally, 1988). Findings by Chambers et al. (2001) indicate an unanimous agreement amongst caregivers that the 24-hour activity of caring was both physically and emotionally exhausting. Ekwall et al. (2005) comment on the implications of an older patient being cared for by someone who is also much older, and state that the physical and emotional toll of caregiving affects various aspects of the life of the caregiver, with decreased time-off affecting their social life, as well as quality of life in general.

Personality and behavioural changes in AD patients are directly correlated with caregiver feelings of burden. Negative interactions between family members also have a negative effect on the health and well-being of carers. The families of AD patients generally experience compromised mental and physical health, financial resources, personal, social, and leisure time, as well as a general decrease in satisfaction with quality of life. Stress symptoms such as fatigue, overwhelming feelings of fear, anger, guilt, the loss of pleasure and motivation as well as sadness and grief are experienced by many caregivers (Gwyther, 1998). In a study by Mohamed (2000), the researcher concluded that it should not be surprising that caregivers of AD patients report chronic fatigue and stress, which are all symptoms of clinical depression as well as expected consequences of the subjective burden that caregivers experience. Mohamed's study indicated that as the level of functionality of the AD patient decreases, so spouse caregivers experience increased feelings of depression and subjective burden.

In a study done by Ferrario, Massaia, Ponzetto, Gambina, Guala and Spadin (1999) amongst 486 caregivers who were members of the Italian Association of Alzheimer Disease (AIMA), the caregivers indicated that the burden they

experienced was mostly due to the patient's restlessness, sleep disturbances, delusions, wandering, aggressive and dangerous behaviours. These caregivers classified the most difficult problems as being the patient's sleep disturbances, dangerous behaviour, mood disturbances, and cognitive problems, with the worst problem being the need for continuous supervision. The determinants of perceived burden seemed to be rather the psychosocial consequences of care rather than managing the patients themselves. Institutional care was usually requested due to the many hours of care required, rather than the behavioural problems. Lack of free time was a great issue for many caregivers; while as many as 85% of the sample group found it difficult to go away on holidays. This and other studies emphasise that caregiving is associated with high levels of perceived strain. This is confirmed by Murray and McDaid (2002), who indicated that in the EURO CARE study, the most consistent finding was the high ratings of carer burden and carer psychological distress across the EU countries.

3.3.1 Caregiver isolation

According to Tebb and Jivanjee (2004), there is a lack of knowledge on the societal level of the biophysical effects that caring for an ADp has on the emotional, social and economic life of the caregiver. Family members, friends, and others withdraw from relationships with caregivers, and isolation is increased by the failure of medical and social service providers to provide information with regard to the expected course of the disease, available services and support. In-depth interviews with caregivers highlight the lack of support, information and monetary assistance as contributors to isolation. Beeson et al. (2000) found that caregivers report feelings of isolation from the community as well as a lack of companionship. This study was conducted using a secondary analysis of data from a sample of 242 husbands, wives and daughters who provided care for AD family members to examine the relationship among loneliness and depression. The researchers found a significant relationship between loneliness and depression, relational deprivation as well as the quality of the current relationship.

Tebb and Jivanjee's (2004) qualitative study designed to examine isolating experiences in the lives of ADps caregivers, find that the latter are isolated in their caregiving tasks because the costs of community care for persons with disabilities and chronic illnesses are not met by society. Caregivers are economically isolated by the shortage of resources, which occurs in the absence of tangible assistance that should be available on a societal level. The lack of economic resources was

found to isolate people even further because of the extent to which financial difficulties and the fear thereof inhibit caregiver participation in social activities, and prevent them from becoming consumers of supportive services. Chambers et al. (2001) maintains that patient antisocial behaviour and aggression are particularly stressful for caregivers, and further contributes to their feelings of frustration and isolation.

3.3.2 Caregiver loneliness

One study undertaken amongst caregiving men and women in a population-based sample aged 75 years and older showed that loneliness was a major predicting factor in the quality of life of caregivers and older people (Ekwall et al., 2005). Hoyer and Roodin (2003) indicate that a link exists between emotional attachments or social ties and loneliness in older people. There is also a correlation between poor health and fewer social contacts; and more social contacts and better health experienced by older people. Older people's sense of autonomy and control are limited by circumstances that could include physical impairments, reduced economic resources as well as a change in residence. Ferrario et al. (2003) stress that caregivers' needs should be identified to determine the most appropriate ways to provide them with the most supportive assistance in their specific circumstances. They add that this can only be done by integrating administrable measures that include intensive research and clinical potential.

According to Chambers et al. (2001), a theme that often recurs in the literature on caregiving is that caring responsibilities restrict caregivers' social lives and amplify feelings of isolation and loneliness. It seems that communication with others is essential and that both formal and informal support systems (in particular contact with other caregivers) are very valuable lifelines. It seems beneficial for caregivers to talk to people who may empathise with their situation. A major source of concern to carers is the anxiety and frustration associated with inconsistent and irregular support as well as the lack of information. Susman (2000) stresses that spouses who care for the patient at home are prone to higher levels of loneliness than those whose spouses are taken care of in a nursing home or other type of facility or institution. Due to the lack of meaningful communication in the home, isolation and loneliness become a significant problem for the caregiver.

3.3.2.1 Definition of loneliness

According to Beeson et al. (2000), loneliness can be conceptualised as a subjective experience in reaction to a perceived lack of the formation and maintenance of meaningful and important relationships (or social contact) with people and things. Reductions in social and recreational activities and changes in one's self-concept and psychological state can escalate into secondary intrapsychic strain of loneliness, which in turn can negatively affect the ADp caregiver's mental health. According to Hoyer and Roodin (2003), two kinds of loneliness can be experienced: firstly, emotional isolation due to the loss or absence of an emotional attachment; and secondly, social isolation that can be attributed to loss or absence of social ties. Both types of loneliness can have the effect that the person experiences a feeling of emptiness and sadness. Beeson et al. (2000) state that although loneliness and depression seem to be related, they are not the same. Loneliness can be defined as the sentiment experienced when a person's lifestyle is deprived of desired relationships, and when current relationships are experienced as inadequate compared to those of the past as well as those anticipated in the future. Furthermore, loneliness could occur due to a lack of relationships such as those enjoyed by other people. The most common antecedent cause of loneliness is the loss of an important person or relationship. In some instances, loneliness can be conceptually defined as a subjective experience in reaction to perceived or actual deficiencies in the opportunity or ability to form and maintain relationships or social contact with people and things that is meaningful or important to oneself. This is especially true for an AD caregiver who might feel alienated from others, with diminished feelings of self-worth and an inability to maintain and develop a positive relationship with the ADp. As people age, the likelihood of experiencing losses increases. When such losses occur it may impede the acquisition of desired relationships as well the maintenance of existing ones, which may further result in increased feelings of loneliness.

3.3.2.2 Loneliness and related factors

Ekwall et al. (2005) conducted a study amongst a caregiving group of men and women aged 75 years and older, investigating quality of life in relation to loneliness, caregiving, social network, gender, age and economic status. The sample consisted of 4 278 people living in Sweden. Of these, 783 (18%) were caregivers. The results indicate that low quality of life amongst caregivers was directly associated with loneliness as well as a weak or nonexistent social network. Loneliness and a small or nonexistent network were significantly associated with

low quality of life among both caregivers, and non-caregivers in the sample. The results showed a significant association between loneliness, weak social networks and low mental quality of life. The fact that loneliness was the most important factor predicting low quality of life among caregivers, as well as older people in general, indicates that it is a crucial factor in the care of older people (Ekwall et al., 2005). At the same time, Hoyer and Roodin (2003) indicate that older people's health is closely associated with the amount of contact they have with family and friends as well as the amount of closeness (or loneliness) they experience. There are indications that older people who are in very good health have more interactions with relatives and friends in comparison to those who experience poor health. Results from research strongly suggest that to maintain closeness with family members and friends, older adults need to possess a certain level of physical vitality without which it may be difficult to maintain reciprocal interpersonal relations. Ekwall et al. (2005) stress that it is advantageous to assist older people to develop and maintain their social networks before these people become too weak, as declining health makes social contacts more difficult.

According to Beeson (2003), loneliness can be seen as a negative experience that implies that a human need is unfulfilled; that is, there is a need for interpersonal intimacy which represents a desire to be related to another person, or in other words, another "self". The experience involves a feeling of being separated. Beeson (2003) further indicates that, according to Fromm-Reichmann, (1959) the longing for interpersonal intimacy stays throughout infancy until adult life, and every person is threatened by its loss. Loneliness can thus be seen as a sense of loss of the other "self", since all people are social beings and need another "self" with whom they can share their feelings, values and decisions. While loneliness is not necessarily due to being alone, it is a reaction to the absence or loss of a much needed relationship with a close attachment figure. Thus the cause of loneliness is the loss of an important person or relationship. Beeson, et al. (2000) confirms that, in the absence of meaningful relationships or social contact, caring for a family member can be stressful and lonely. This is especially true for the AD caregiver who might feel alienated from others as a result of their duties.

According to Beeson et al. (2000), very few studies address the loneliness factor in the AD caregiver. In one phenomenological study, the most common theme was loneliness and aloneness. In a later study, Beeson (2003) confirmed that the loneliness reported by the caregiver corresponded with relational deprivation, loss

of self, and depression; and that AD spousal caregivers' depression was determined by loneliness. This study involved 49 AD caregiving spouses who were compared with 52 non-caregiving spouses, and found that the AD caregiver group experienced much higher levels of loneliness and depression in comparison with the non-caregiving group. Ekwall et al. (2005) found that gender differences in people's experiences of loneliness showed higher frequencies of intense feeling of loneliness for women than for men.

3.3.3 Caregiver depression

Hoyer and Roodin (2003) indicate that caregivers' risk for depression increases when they care for older relatives with behavioural problems as well as cognitive impairments; when they experience significant role conflicts with employment and family; and when they feel captive in the caring role. Depression is a great contributor to the burden experienced by the caregiver and can serve to negate any rewards and recognition that the caregiver might receive. Taylor (2006) emphasises that providing care over the long-term has been linked to psychological distress that includes anxiety and depression, and also compromises the caregiver's physical health. This is especially relevant with regard to ADp caregivers since the caregiving process can extend over many years, even 10 years or more, with the result that the caregiver's health and psychological well-being is at tremendous risk, and the chances of stress-related illnesses such as depression and anxiety are greatly amplified. Larrimore (2003) confirms that long-term caregiving is associated with an increase in the risk for both physical and mental problems, which may include depression-impaired immune response, anxiety, family discord, and social isolation. It seems clear therefore that caring for AD patients can have psychologically distressing effects on the caregiver.

3.3.3.1 Definition of depression

Ross and Deverell (2004) stress that depression can be defined as anger that has been turned inwards towards the self. For example, caregivers may blame themselves for not having been able to prevent the illness. People who are depressed often perceive themselves as of less importance. Their sense of having no value may be linked to the fact that they are powerless to alter or change something, such as their circumstances (Ross & Deverell, 2004). According to Beeson (2003), although lonely people often exhibit features of depression, the opposite is not true. Depression does not necessary imply a feeling of loneliness. Although loneliness and depression are strongly linked historically in the literature,

they should be considered two distinct constructs that may overlap and contribute to each other.

Ross and Deverell (2004) stress that a distinction should be made between endogenous depression, which can be related to a chemical imbalance in the body and is usually internally generated, and reactive depression, which is a normal response and grief reaction to a traumatic experience (such as AD caregiving). According to Taylor (2006), some of the physical signs of depression include fatigue, sleeplessness and weight loss. There is also some evidence that physical factors might predict depression better and earlier in chronic illness, while psychological factors may explain depression later in the illness. According to Taylor (2006), research done by Herbert and Cohen (1993b) also suggests that a relationship exists between depression and immunity to the effect that the more depressed a person is, the more cellular immunity is likely to be compromised.

3.3.3.2 Depression and related factors

Beeson et al. (2000) report on a study undertaken with 242 husbands, wives and daughters who provide care for an AD family member to examine the relationship between loneliness and depression. Results show that the more loneliness reported by the caregiver, the more depression, relational deprivation and poorer relationship quality they experienced. Loneliness was the only variable found to be significant in the prediction of depression amongst caregiving husbands, wives and daughters. In another study, Beeson (2003) found that AD caregiving spouses consistently report higher levels of loneliness and depressive symptomatology than non-caregiving spouses. Thies's (2004) findings agree that depression amongst AD caregivers is three times that of other people in the same age group.

A statistical analysis was done in a study that involved 34 female Italian Alzheimer's caregivers over a total of 816 caregiving days revealed a positive relationship between levels of anxiety, depression and hours of care, and levels of physical and psychological illness (Sansoni, Vellone & Piras, 2004; Mausbach, Patterson, Von Känel, Mills, Ancoli-Israel, Dimsdale & Grant, 2006). These researchers further found a negative correlation between level of education and time for leisure activities. Thus it seems evident that the support and assistance given to Italian caregivers might be far from adequate, particularly when it comes to respite services and educational support. Danhauer, McCann, Gilley, Beckett, Bienias and Evans (2004) report on a study that made use of a random effects

model to examine the association between behavioural disturbances in patients with AD and caregiver depressive symptoms at two-month intervals over a period of 18 months. This study indicated that the total behavioural disturbances were associated with higher levels of caregiver depressive symptoms, and attributed this effect primarily to the patients' aggressive behaviour.

3.4 Burden of Care

According to Fernandez-Ballesteros (2003), caregiver burden can be seen as the physical, psychological and social consequence associated with caring for a patient. Murray and McDaid (2002) indicate that carer burden is usually the effect of long-term cost, and the effect of this in turn on the morale of the carer.

Although caregiving can also have positive aspects, the term burden is often used with a negative connotation, and usually refers to the total impact of the caregiving role where feelings of entrapment, loss and social isolation are common. Murray and McDaid (2002) note that the effect that caregiving has on the individual may differ greatly, while the size of burden can vary accordingly. The nature of the relationship and the living arrangements may also play a major role (Murray & McDaid, 2002). Fernandez-Ballesteros (2003) further indicates that stressors are usually due to the problematic and difficult conditions that the caregivers experiences. There are, however, also moderators, comprised of social, personal and material resources, that can help to modify or regulate the causal relationship that exists between the stressors and outcomes; as well as the escalation of stressors even outside the boundaries of caregiving (such as the caregiver's career). Coping abilities and social support can potentially intervene as buffers in the stress process.

3.4.1 Definition of burden of care

Hoyer and Roodin (2003) define the concept 'burden of care' on two levels. Firstly *objective burden* can be defined as the extent of the changes that occur in various aspects of the caregiver's life and household; while *subjective burden* can be defined as the caregiver's attitude or emotional response to the caregiving task. Objective caregiver burden (OB) thus refers to the disruption in routine or lifestyle,

changes in finances, family and other social activities. Subjective caregiver burden (SB) concerns emotional reactions to the caregiving task, and can include feelings of guilt, embarrassment, anger and other emotions. Ho, Friedland, Rapport and Noh (2003) see burden as the feeling aroused by caregiving demands and stress.

Both OB and SB are relevant to caregiving of the ADp since behavioural problems cause tremendous stress for the caregiver, and are also appraised differently by individual caregivers. Caregiver burden can thus be seen as the physical, psychological and social consequences of taking care of a patient, and can be examined in terms of either objective or subjective burden. Moderators that help to ameliorate the burden experienced by caregivers can be of a social, personal and material nature. Studies indicate that behavioural problems seem to be the most difficult to manage, and increase caregiver burden over time (Fernandez-Ballesteros, 2003). Ho et al. (2003) propose that caregiver burden be seen as the caregivers' perceptions of the negative impact of their caregiving role. They further indicate that the caregiver's coping ability, personality traits, availability of social support, patient's behaviour as well as cognitive impairments are all factors associated with the way burden is perceived.

Jansson et al. (2001) state that invisible caregiving does not necessarily include overt behaviour, and the patient is not always aware of this. Nonetheless, this aspect of caregiving is extremely important to the caregivers' experience, as well as to understand caregiving from the caregiver's perspective. Caregiving is a physically demanding task and greatly contributes to the burden as perceived by the caregivers. The invisible care as well as instrumental care severely impacts on the caregiver's chance for an independent life. According to Donaldson and Burns (1999), caregivers' own characteristics may play a major role in determining how burdensome and stressful they find their role. These characteristics include gender, availability of a support system and the caregiver's relationship with the patient. Additional factors are the patient's symptoms and how the caregiver perceives him or her, as well as the caregiver's attitude and behaviour towards the patient.

According to Fernandez-Ballesteros (2003), researchers frequently conceptualise caregiver behaviour in terms of specific tasks relating to activities of daily living (ADLs). The emphasis on tasks is important but may mean that caregiving is understood only in terms of objective burden. The subjective burden is therefore

downplayed. This pattern may extend to the many other areas of the caregiver's personal life that are embedded in relationships of a personal nature.

According to Gwyther (1998), ADp caregivers pay a high financial, social and emotional price. It is therefore crucial for families to be able to cope effectively with the disease and so decrease the harmful effects on the family and minimise conflict. It is said that by living with AD it is a matter of learning to "bend without breaking" (Gwyther 1998). To live with AD implies a permanent imbalance in the normal "give-and-take" of family relationships. Murray and McDaid (2002) indicate that economic and social burden are represented by economic costs such as time involved with the caregiving process as well as out-of pocket expenditure. Unwaged caregivers also face costs due to their inability to perform normal household chores such as childcare, gardening and participation in voluntary activities or other communal duties. An article in Drug Week (Relief falls short..., 2004) mentions that monetary assistance from government and other services is lacking, while emotionally, caregivers report that they feel isolated socially due to loss of free time, friendships, and so on. It thus seems that ADp caregivers in general experience a lack of adequate instrumental or material support, which can also be related to the need for more formal help for families who carry the main burden by "providing their own welfare services".

About 60% of total cost for dementia care in the UK is carried by informal carers, meaning that the carers carry the bulk of the economic burden of caring for dementia patients (Bosanquet, 2001). Thies (2004) found that at least 70% of caregivers make contributions from their own personal income and savings towards caring for their relative. Thies (2004, p. 57) further states that "the imminent epidemic of Alzheimer's disease threatens to bankrupt Medicare and Medicaid". Due to the time that is involved for the caring of the patient, a carer's paid working hours may be drastically reduced or may even cease completely. This is compounded by the loss of income from the patient's earnings. Bosanquet (2001) furthermore stresses that many out-of-pocket expenses incurred by the informal carer are not reimbursed. These may include items such as housing alterations and transportation.

Murray and McDaid (2002) emphasise that informal caregiving can have devastating consequences not only for the psychological and physical health of the caregiver, but also in financial terms. Caregivers' own health may deteriorate to

such an extent as a result of the mental and physical strains of caring that they become isolated from friends, family and social networks. This is when the caregiving becomes a full-time career.

3.4.1.1 Subjective versus objective burden

According to Fernandez-Ballesteros (2003), the primary demands of the caregiving process, namely, managing the patient's needs and the sense of overload, constitute the objective burden. This is also referred to as the primary stressor. The subjective burden may be seen as the secondary stressor that arises as a result of the primary stressor, and includes role strain outside of caregiving. Such difficulties include career concerns as well as intrapsychic strain. Hoyer and Roodin (2003) stress that caregivers are at higher risk for mental health disorders (such as depression) than for physical health problems. This thus suggests that subjective caregiver burden is a better predictor of mental health problems than objective caregiver burden.

However, Gonyea, O'Conner, Carruth and Boyle (2005) note that many studies on AD caregiver burden have focused on the role of objective factors as supposed to subjective factors. Although objective variables such as caregiver age, patient dementia severity, and functional status have shown to be significantly associated with the burden experienced by the caregiver, the correlations are generally modest, and are very limited in their ability to explain the variability in caregiver outcomes. While it is a generally well-established fact that caregiving is burdensome it is further believed that caring for a dementia patient can be the greatest challenge of all (Fernandez-Ballesteros, 2003).

3.4.1.2 Burden of care and related factors

According to Fernandez-Ballesteros (2003, pp. 161-162), "the objective (primary demands of caregiving) and subjective burden (secondary demands involving dislocations) are determined by four sets of variables: (1) the past and present quality of the relationship between caregiver and care recipient, (2) the role's reverberations in other life spheres, (3) the support available from the caregiver's social ecology and (4) psychosocial variables of the caregiver." At the same time Ho et al. (2003) list caregiver coping and personality traits, the availability of social support, the patient's behaviour and cognitive impairments as factors associated with the way burden is perceived.

3.4.1.3 Experience of burden of care

Ferrario et al. (2003) indicate that, apart from the long duration of the illness, which has a negative effect on the family relationships, especially women caregivers who are unemployed report a higher level of emotional distress and very limited social involvement. It is evident that caregivers who are employed perceive their lives in a more positive way than unemployed caregivers. These researchers further found that spouse caregivers reported greater perceived burden than did child caregivers, which may be attributed to the fact that child caregivers were mostly still working and may have had more opportunities for other activities as well as other familial affective points of reference that could be compensative. Welleford et al. (1995) add that the ability to cope with problems is based on a person's personality, and that people dealing with similar problems perceive them in a different way. It is evident from their and other research that caregivers experience burden differently and that some adapt more successfully than others. In this study a significant relationship was found between the perceptions of patient personality as well as the caregiver personality and the burden experienced by the caregiver. It could thus be extremely important for cognitive and supportive interventions to consider how caregivers perceive specific behaviours and interferences negatively.

3.4.2 Risk factors that contribute to burden

Fernandez-Ballesteros (2003) indicates that burden could include risk factors such as the deterioration of the relationship between carer and patient, the spouse's poor self-rated health, length of caregiving, increase in the physical disability as well as behavioural and mood disturbance of the patient. Caregiver burden can also be explained by the relation of exposure to stress, plus the vulnerability caused by a lack of psychological and social resources (caregivers who are high on vulnerability and low in resources will have a higher burden). Rymer, Salloway, Norton, Malloy, Correia, and Monast (2002) undertook a study with 41 participants that had AD and their caregivers. They found that both the patient's awareness of memory deficit as well as behavioural disturbances had an effect on caregiver burden, with behavioural disturbances as the major contributor. Gwyther (1998) indicates that periods of patient lucidity and insight, and vestiges of the patient as he or she was before AD, might continue well into the course of the disease. This can be a very difficult and confusing encounter for the caregiver, and make it especially difficult for the family to cope. In addition to this, they must deal with the knowledge that their relative's condition will gradually deteriorate until eventual he or she will not recognise those closest to him or her.

Chappell and Reid (2002) found that caregiver well-being is directly affected by variables such as perceived social support, burden, self-esteem and hours of informal caregiving. Murray and McDaid (2002) add that the caregiving task is likely to force carers to forfeit leisure time, which has an impact on their social relationships and thus the possibility of getting respite from the caregiving task. These authors recommend that future policy should focus on psychological measures of burden in addition to economic parameters. There is a definite need for the identification of both the cost of informal care and motivating factors involved in caregiving to be able to support carers in the best possible way.

3.5 Stress and Coping

Because caring for a dementia patient is a highly demanding and stressful job, researchers have studied the effect of caregiving using Lazarus and Folkman's (1984) model of stress and coping (Morano, 2003). This model postulates that stress is the perception that one's resources are under attack, and that the person responds to this threatening experience accordingly. Among the many difficulties reported by AD caregivers, the most common ones are those associated with assisting patients with ADLs such as dressing, bathing, as well as having to cope with their limited cognitive abilities and behavioural problems. The degree of perceived problems correlates with (among other things) poor caregiver-patient relations, higher levels of anxiety, hostility as well as caregiver depression (Cavanaugh, 1997). Gwyther (1998) stresses that what makes AD so remarkable is that it affects the individual cognitively, functionally, behaviourally, socially and physically. What makes it more difficult is that the development and course of AD symptoms is highly unpredictable and heterogeneous. People with AD have variable capacity, for instance in decision-making; the ability to perform some ADLs may be affected, while some of the other abilities will remain intact.

Cavanaugh (1997) further indicates that complications relating to behavioural problems in patients seem to be more negatively experienced by caregivers especially if they have had to deal with emotional outbursts. This is in keeping with Lazarus and Folkman's suggestion that it is not what happens, but the way the person perceives what happens, that matters. Therefore, it is the perception that a

person's resources are under attack by the current circumstances that is the cause of the burden, and not the objective situation as it occurs in reality.

3.5.1 Stress and burden

Fernandez-Ballesteros (2003), use the stress model as a conceptual framework for explaining burden. The physical overload of stress is explained by the assistance that is rendered to aid patients in performing the ADLs. However, the psychological and social costs of the caregiver role are much more difficult to measure. Determining the stress of the caregiving role is one way of doing so. Caregiver burden can thus be seen as the physical, psychological and social consequences of caring for a patient. Stressors can be seen as the problematic conditions and difficult circumstances that are experienced by caregivers. Social, personal and material resources may modify or regulate the causal relationship that exists between stressors and outcomes, and may help the caregiver cope with the increase of stressors outside the caregiving boundaries.

3.5.2 Primary and secondary stressors

Murray and McDaid (2002) list the task of caregiving and the time it takes to carry out these tasks as a primary stressor. Secondary role strain is indicated by role and relationship conflicts which take place within the home or in the wider social environment. The carer's subjective appraisal of the caregiving tasks and his or her performance thereof are indicated as intrapsychic strain. Fernandez-Ballesteros (2003) agrees that the objective conditions of caregiving (the management of the patient's needs) are the *primary stressors*, and contribute to the subsequent sense of overload. *Secondary stressors* arise from the primary stressors and could include intrapsychic strain as well as strains due to roles outside of caregiving. Murray and McDaid. (2002) confirm that three forms of stress can be related to the burden experienced by caregivers: *primary stressors*, which are the tasks and time involved with caregiving, *secondary role strain*, which takes cognisance of role and relationship conflicts within or outside the caregiving environment, and *intrapsychic strains* that include the caregiver's subjective appraisal of how well he or she is performing as caregiver.

Hardships and problems that are directly anchored to the caregiving role can thus be seen as primary stressors, while secondary stressors are experienced due to strain that is experienced outside of the caregiving role. Thirdly, intrapsychic strains exist that could involve a diminished self-concept. Along with the stress process,

coping and social support have the ability to intervene as buffers at several stages of the illness (Fernandez-Ballesteros, 2003).

3.6 Conclusion

Howcroft (2004) concludes that investigations into the burden experienced by caregivers show that burden is associated in principle with a lack of social support as well as increased behavioural problems in the patient, and not cognitive and functional problems. With the progression of the illness as well as the increase in caring responsibilities, health and social services need to assist the caregiver in continuing to manage the caring process. Ho et al. (2003) describe the negative impact of the caregiving role and the caregiver's perception thereof as "caregiver burden," which may be tempered by social support. Furthermore, caregivers' ability to cope as well as their personality traits, the availability of social support and the patient's behaviour and cognitive impairments are all factors associated with the way that burden is perceived.

The following chapter addresses the role of social support in the caregiving process.

CHAPTER 4

SOCIAL SUPPORT AND THE CAREGIVING PROCESS

4.1 Social Support

Cohen and Syme (1985) indicate that since the 1970s, interest in the concept of social support and its effects on health and well-being has increased. This is reflected in the vast increase in research as well as the number of treatment and intervention programmes that include social support as part of therapeutic assistance. The increased interest in social support can further be attributed to the role it plays in the *aetiology of diseases and illness*. Another reason for this could be the role that social support plays in *treatment and rehabilitation programmes* that are instituted at the onset of an illness. The benefits of altering behavioural characteristics in these treatment and rehabilitation programmes are widely recognised. Hoyer and Rooden (2003) indicate that social activity or frequency of interaction declines as people become older. Because social support is essential to well-being, investigators have studied these age-related changes. Results suggest that older people are more selective in their social interactions and engage in fewer social exchanges. In general, older adults seek social interactions that are emotionally rewarding. However, social support is one of the more critical dimensions that contributes to well-being and reduces stress among older people, and especially women.

4.1.1 Definitions of social support

According to Ogden (2004), social support was initially defined by taking cognisance of the number of friends an individual has; but this definition has been extended to include the person's satisfaction with the support that is rendered. Social support could include *esteem support*, whereby a person's self-esteem is boosted by other people, *informational support* that includes information provided by other people, and *social companionship*, which consists of support rendered by means of activities. Finally, *instrument support* involves a form of physical assistance. DiMatteo and Martin (2002) note that social support has been defined

as any input that can further the goals of the receiver. Social support can be tangible, including provision of physical resources that can be beneficial to the individual in some way, or psychological, that assists the individual in developing emotional well-being

Social support can also be explained as the specific people or community resources to which an individual turns for emotional and instrumental assistance (Ross & Deverell, 2004). While Chambers et al. (2001) state that social support could be defined as the active participation of significant others in the caregiver's efforts to manage stress, caregivers can easily become isolated from social support as a result of their confinement and responsibilities, which places them increasingly at risk for stress-related illnesses. Both the caregiver's as well as the patient's quality of life can be adversely affected, as social support is important for coping and satisfies the need for attachment, a feeling of self-worth, stress relief, and so on. However, DiMatteo and Martin (2002) emphasise that social support can be defined as any action that is to the advantage of the receiver of such support.

4.1.2 Types of social support

DiMatteo and Martin (2002) indicate that two major types of social support can be distinguished: *tangible* support, which may include physical resources that could be beneficial to the receiver; and *psychological support*, which assists the receiver in developing beneficial affective or emotional states. Psychological support helps a person to feel more content (or to feel better). It is clear that social support from family and friends has an important role to play in assisting a person "to translate intentions into health behaviours" (DiMatteo & Martin, 2002, p. 232) while the absence of social support can have a detrimental effect on the individual's overall health. Social support can also consist of support from individuals such as friends, family members, neighbours, co-workers, professionals and acquaintances. All types of support have been found to be beneficial in helping individuals to cope during a serious illness. There is enough evidence to suggest that in general people who receive support enjoy better health than those who do not receive such support.

As indicated above, social support includes several forms of assistance such as appraisal support, tangible assistance, information, and emotional support. A study done amongst more than 400 spouse-caregivers, of whom 40% were husbands and 60% were wives, showed that when caregivers received a few individual and

family counselling sessions with a further option of telephone counselling as needed, and joined a support group, caregiving stress over the duration of the illness was reduced (Mittelman, 2002). The alleviation of stress can have a positive impact on both the family caregivers as well as the relatives who are suffering from AD. The general introduction of this kind of intervention could have a vast impact on both the emotional and financial cost of AD, both on those involved as well as society at large.

4.1.2.1 Appraisal support

Taylor (2006) indicates that *appraisal support* includes assisting an individual to employ the necessary coping strategies and resources to deal with specific stressful situations. By exchanging different appraisals and making suggestions on how to manage events, individuals facing stressful events can develop a better idea of the severity of the situation and find ways of managing these events.

4.1.2.2 Tangible assistance

Tangible or instrumental support comprises advice as well as assisting with physical tasks such as shopping (Ho et al., 2003). *Tangible assistance* can also involve material support such as monetary assistance, services and goods (Taylor, 2006). DiMatteo and Martin (2002) suggest that the provision of tangible support in the form of physical resources such as running errands, lending money, and so on, friends and family can be of great assistance to the person in need and can help reduce their stress.

4.1.2.3 Informational support

Taylor (2006) indicates that family and friends can provide *informational support* in stressful situations by providing information about similar situations that they have experienced. DiMatteo and Martin (2002) agree that other people in a person's social world can provide information about alternative actions that could solve or reduce the stressful situation. This assists people to look at the problem from another angle and has the effect of minimising or buffering the impact that it would otherwise have.

4.1.2.4 Emotional support

Emotional support from friends and family can be of great assistance in assuring people of their own value and providing a feeling of self-worth and the feeling of being cared for. This can all help to curb bouts of depression and other health-

related issues caused by stress (DiMatteo & Martin, 2002; Taylor, 2006). Ho et al. (2003) suggest that *emotional support* can derive from informal as well as formal sources, including friends, family, institutions and service groups. Ho et al. (2003) reported that emotional support from family was crucial to lessening the caregiver's psychological burden.

4.1.2.5 Formal support

Formal support is normally rendered through government-supported home-care programmes. Even in the instance where tangible support from the community was provided, the caregivers' burden was lessened especially when caregiving tasks were rendered by the formal sector (Ho et al., 2003). Ho et al. (2003) further reported that support allowed caregivers to see their situation in a more positive light, because they could identify with others in the same situation. According to Bosanquet, (2001) the rapid increase worldwide of the numbers of patients with AD and other dementias, it is of the utmost importance that health professionals, especially those that are involved in planning for current and future healthcare service provision, should recognise that help is needed for the management of this disease.

4.1.3 Social support and psychological status

Taylor (2006) states that social support effectively reduces psychological distress. Chambers et al. (2001) note that carer support enhances care competence and can reduce the need for hospitalisation and intervention from health care professionals. Caregivers that do experience drastic life changes can become isolated from social support as a result of their responsibilities and confinement, and are therefore at risk for increased stress and depression. All of this does not only affect the primary caregiver, but also influences the patient's quality of life. The importance of social support should be stressed as it satisfies the need for attachment, relieves stress and bolsters a sense of self, which forms part of general coping ability. According to Taylor (2006), a person's psychological status may influence their susceptibility to physical illness through the effect it has on cardiovascular, endocrine and immune system functioning, as well as changes in other health-promoting behaviours. DiMatteo and Martin (2002) indicate that social support may render potentially stressful events more benign by diffusing or minimising their initial impact. Social support may also encourage a more positive outlook on life as well as a greater sense of self-esteem. All of these positive psychological outcomes may manifest in the individual's greater resistance to

disease and could even motivate people to engage in more positive preventive health habits.

4.1.3.1 Social support and alleviation of the impact of stress

According to Chambers et al. (2001), research on the stress process indicates that coping and social support are resources that influence the extent to which a stressful situation (such as the duties and responsibilities of caregiving) affects psychological well-being. They found that both formal and informal support systems can be important lifelines. Fernandez-Ballesteros (2003) identifies primary stressors as being hardships and problems that are directly anchored in the caregiving stressors, and secondary stressors as the strain experienced in roles and activities outside the caregiving role. Intrapsychic strains involve the diminishing of the self-concept. This author notes, however, that social support can intervene as a potential buffer at different points in the stress process.

The long-term caregiving task is associated with increased risk of physical and mental health problems, including depression, impaired immune response, anxiety, family discord and social isolation (Larrimore, 2003). The literature is consistent in indicating that caring for an ADp is psychologically distressing; and that moderators consist of social, personal and material resources that help regulate the relationship amongst stressors and outcomes. Taylor (2006) adds that people may suffer emotionally during stressful times, which can escalate into depression, anxiety, sadness and loss of self-esteem. Family and friends can provide emotional support insofar that their warmth and nurturance can enable people to cope better with stressful circumstances.

4.1.3.2 Social support and prediction of morbidity and mortality

Social support seems to modify the effect of stress on immune functioning. It also seems that social support buffers the effects of stressful events in the sense that the situation seems less frightening and is appraised as less threatening. DiMatteo and Martin (2002, p. 375) state that, “by rendering stress less likely to trigger deleterious physical responses (such as poor health habits or chronic, exhausting physiological arousal)”, potentially stressful events are rendered “more benign by diffusing or minimizing their initial impact”.

Taylor (2006) further indicates that social support enables people to handle serious medical conditions and disorders better than those without such support. In a

study by Mausbach et al. (2006), the researchers found that a significant relationship existed between patient behavioural problems and caregiver psychiatric symptoms. Furthermore, they indicated that the relations between role overload and psychiatric morbidity was significant when mastery was low; and that caregivers with a greater sense of personal mastery may be protected against the negative effect of caregiver stress.

In an earlier study, House (1987, p. 136) found evidence from diverse types of studies that social support can reduce “morbidity and mortality, lessen exposure to psychosocial stress and perhaps other health hazards, and buffer the impact of stress on health.” DiMatteo and Martin (2002) conclude that people with extended social networks and community ties live longer than their peers without such ties. Ogden (2004) agrees that social support predicts a decrease in mortality rates, thus indicating the role that social support plays in overall health. In addition, single individuals have higher mortality rates from heart disease than married people, which suggests that heart disease and mortality are related to lower levels of social support.

4.1.4 Therapeutic effect of social support

Taylor (2006) proposes that studies support the notion that social support can effectively reduce psychological distress (including depression, anxiety and other psychological illnesses) during stressful circumstances. In addition to providing psychosocial benefits, social support also appears to reduce the likelihood of illness and to speed up recovery from illness. According to DiMatteo and Martin (2002), it is clear that social support helps individuals to obtain a more positive outlook on life, increases self-esteem and resistance to illnesses, and encourages people to engage in more positive, health-promoting behaviours. The form of social support received can play an important role. For example, if someone needs emotional support and receives only tangible support, it can further add to the person’s frustration and stress. Ogden (2004) shows that immuno-suppression may be reduced by social support, which confirms the notion that social support promotes health in general. Taylor (2006) indicates that people with a high quantity and sometimes a high quality of social relationships have lower mortality rates. Social support appears to help people to effectively resist illnesses and minimise complications from serious medical conditions.

4.2 Theories of Social Support

Two theories that explain the role that social support plays in the health status of individuals are the *main effect hypothesis* and the *buffering hypothesis*.

4.2.1 Main effect hypothesis

The *main effect hypothesis* sees social support as beneficial and the absence thereof as stressful. It suggests that the mere presence of social support reduces the stressor while the absence of social support acts as the stressor (Ho et al., 2003; Ogden, 2004). Social support is thus suggested to have a mediating effect on the stress-illness relationship, whereby the presence of social support reduces the effect of the stressor and the absence thereof acts as a stressor in itself. Taylor (2006) agrees, stating that the basis of the main effect hypothesis is that social support is beneficial during both highly stressful as well as non-stressful times.

4.2.2 Buffering hypothesis

The *buffering hypothesis* proposes that social support acts as a buffer by mediating the link between stress and illness. Social support enables people to compare themselves with others and in so doing select appropriate coping strategies (Ogden, 2004). According to Taylor (2006), the *buffering hypothesis* maintains that the health and mental health benefits are evident during stressful times, although during periods of little stress social support might have negligible physical or mental benefits. According to the *buffering hypothesis*, therefore, social support acts as a reserve and resource that enables individuals to cope more effectively when high levels of stress are experienced. Ho et al. (2003) assert that the relationship between stress and health is mediated by social support, and suggest that social support assists individuals to change their roles or identities (as demanded by the stressor) as they can relate to others who have experienced similar stress. According to Ho et al. (2003), the *buffering model's* explanation of the positive influence of support during stressful events is confirmed through studies which report that increased support from family is associated with a decline in reported caregiver burden.

4.3 Social Support and the Alzheimer Caregiver

According to Tebb and Jivanjee (2004), there is a lack of knowledge of the biophysical effects of caring for an ADp on the emotional, social and economic aspects of the caregiver. Family members, friends, and others withdraw from relationships with caregivers, and isolation is exacerbated by medical and social service providers, who offer little support and fail to provide information on the expected course of the disease. Caregivers have indicated lack of support, information and monetary assistance as contributors to isolation. Lack of economic resources can isolate people even further because existing or potential financial difficulties inhibit participation in social activities and use of supportive services. Taylor (2006) states that social ties and relationships with others are associated with emotionally satisfying aspects of life. Social support can reduce the effects of stress, help people to cope with stressful events and help prevent stress-induced illness.

4.3.1 Benefits of social support

The enormous benefits of social support and the effect it has on the functioning of the cardiovascular, endocrine, and immune systems has been mentioned in a previous section. Social support is one of the major factors that assist individuals to deal with stressful situations and circumstances (DiMatteo & Martin, 2002). Many research studies confirm that people who are better integrated into a social network tend to live longer and are less susceptible to infectious diseases than people without such social networks (Fernandez-Ballesteros, 2003).

4.3.1.1 Social support and psychological well-being

Morano (2003) stresses the importance of empowering caregivers by developing interventions that focus on coping skills as well as the manner in which caregivers appraise situations. Tebb and Jivanjee (2004) recommend that caregivers be supported through the provision of resources that curb the isolating effects of caregiving.

According to Hamdy, Turnbull, Edwards and Lancaster (1998), support groups may be beneficial sources of support. Here, people openly discuss their problems and share their emotions with others that are in similar situations, which can help to

ease the physical and mental stress involved in caregiving. Through education, support and experience, caregivers can develop increased competency in their ability to handle various caregiving-related problems. The above authors suggest that the health care team should work together to facilitate the information exchange and support that both professional and family caregivers need to enable them to render essential care to AD patients. Pillemer and Suitor (2002) state that support from an experientially similar peer (a person that has experienced the same stressful situation) can lead to more positive outcomes among caregivers of ADps.

Chambers et al. (2001) indicate that, despite the phenomenal contribution rendered to society by carers, the vast body of evidence indicates that these people's needs are largely ignored. These authors further indicate that coping and social support are the main resources that influence the extent to which a stressful situation affects the psychological well-being of people, and thus could have a major influence on caregivers' functioning. In Ho et al.'s (2003) study undertaken with Chinese-Canadian female caregivers, ongoing mechanisms and social support appeared to mediate the participants' stress. This study examined the social and psychological experiences of Chinese-Canadian women who were taking care of AD relatives. Apart from the fact that their caregiving role was seen as a cultural obligation, and the fact that they accepted this role, they shared with most other caregivers a feeling of being overwhelmed, anxious and fearful of what the future holds. Notwithstanding the fact that they accepted their roles as caregivers and the fact that they felt well supported by informal and formal support systems, the participants experienced secondary stressors similar to that experienced by caregivers in mainstream Western society.

4.4 Conclusion

There is enough research evidence to indicate that social support buffers individuals from the negative effects of stress. ADps caregivers must deal with an ongoing, chronic, deteriorating illness, and require knowledge to understand the full implications of this illness on caregivers and the role that social support systems should play. Unfortunately, support for caregivers is not always available. Alzheimer's South Africa (2004) confirms that there is no specific government policy in relation to dementia; home-based care is generally the only feasible option

as institutional care is not within the means of most South Africans. Chambers et al. (2001) confirm that the burden of care for AD patients seems to fall exclusively on the family, who is usually unprepared for this new role. Caregivers dealing with an illness such as AD, with an insidious onset and its chronic progressive nature, might benefit from a number of different interventions that could have a combined effect (Bosanquet, 2001). Dealing with the demands generated by the increasing number of AD patients, and finding ways to integrate different intervention strategies, pose a challenge for healthcare officials.

In the light of the above, this study aims to investigate the relationship between social support and psychological health (depression, loneliness and perceived burden of care) amongst a cohort of Alzheimer's caregivers. Both caregiver and patient characteristics are investigated as research indicates that these play a role in the psychological health outcomes of the caregiver. The methodology used to investigate these relationships is discussed in the following chapter.

CHAPTER 5

METHODOLOGY

The purpose of this chapter is to describe the research design of the study. The research questions and process of data collection are discussed. Ethical considerations of the research and psychometric properties of the measures utilised are also included in this chapter.

5.1 Research Design

This is a quantitative exploratory study. Its aim was to explore the relationship between variables such as real and/or perceived social support (SS), depression (D), loneliness (L) and burden of care (BOC) in a group of ADp caregivers. The relationship between the cognitive status of the patient and the caregiver's psychological status was also taken into consideration.

The study employed a non-experimental correlational design as it investigated social support as perceived by the ADp caregiver and its effect on the caregiver in relation to burden, feelings of loneliness and depression. It was expected that real and/or perceived social support could moderate or mediate the relationship between loneliness and depression, and lessen the sense of burden of care experienced by caregivers. Patient characteristics and caregiver characteristics were included in the analysis as research has shown that these influence the psychological health of caregivers. For example, in a study on 41 ADps and their caregivers (Rymer et al., 2002), it was concluded that both patient awareness of memory deficit and behavioural disturbance impacted on the burden experienced by caregiver, with the greatest contribution being behavioural disturbances.

5.2 Study Aims

The aims of this study were to establish caregiver levels of real and/or perceived SS, D, L and perceived BOC, and to investigate whether relationships exist between real and/or perceived SS, D, L and BOC. The study further aimed to

explore whether a relationship exists between the cognitive status of the patient and the affective status of the caregiver. The affective status of the caregiver and caregiver characteristics were thus also investigated. According to Donaldson and Burns (1999), caregivers' own characteristics may play a significant role in determining how burdensome and stressful they find their role. Caregiver characteristics include, among others, gender, availability of support systems and the caregiver's relationship with the patient. Caregivers' perceptions of the patient's symptoms, as well as their attitude and behaviour towards the patient, can also impact on their perception of burden.

Caregivers commonly report a lack of social support, which corresponds with feelings of loneliness, depression and burden of care. This study intended to ascertain whether this sample also reported a lack of real and/or perceived social support, and how this correlates with feelings of loneliness, depression and burden. Caregiver and patient characteristics were examined to determine whether these influenced caregivers' experience of burden. Emphasis was thus placed on the effects of this illness on caregivers who are exposed to extreme, stressful circumstances; and then specifically on the role played by real and/or perceived social support in the caregiver's experience of burden, loneliness and depression. To recapitulate then, this study aimed to elucidate the relationship between various psychological components of the caregiving process.

5.3 Sampling

The criteria for participation in the research study were that the caregiver should be personally taking care of the patient. He or she could be a spouse, child or nurse who lives with the patient and acts as the primary caregiver. The greater ADp caregiving fraternity was accessed to obtain as large a sample as possible. Various groups were approached to obtain the assistance of as many caregivers as possible, including Alzheimer's South Africa support groups, neurologists and individuals.

The Regional Director, Gauteng Region of Alzheimer's South Africa provided assistance by approaching 11 Alzheimer's support groups in the Gauteng area. Support group facilitators also assisted by distributing the self-administered

questionnaires among the caregivers in their groups. In addition to Gauteng groups, Alzheimer's support groups in Mpumalanga, North West, and Limpopo were also involved in the study. A sample of 40 voluntary participants was obtained for this research, which may be considered an adequate size for statistical purposes.

Although the research was restricted to certain geographical areas (support groups in areas of Gauteng, Mpumalanga, Limpopo and North West), the findings of this study may hopefully provide a foundation for a greater understanding of the needs of ADp carers throughout South Africa.

5.4 Ethical Considerations

An introductory paragraph in the questionnaire clarified the role and background of the researcher and outlined the data collection procedure. The necessary precautions were taken to ensure that potential ethical dilemmas were anticipated and addressed. Respondents were assured that their identity would be protected and that their personal particulars would not be disclosed to any third party. Participation was voluntary and respondents had a choice to withdraw at any stage. Respondents were informed of the approximate time needed to complete the questionnaires. All respondents were required to sign a consent form indicating that their participation was voluntary and that they understood the intention of this research. Integrity and respect for the participants of the study was a primary prerequisite.

5.5 Data Collection and Measuring Instruments

In order to achieve the aims indicated above, data were collected using the following standardised measuring instruments.

5.5.1 Zarit Burden Interview (ZBI)

5.5.1.1 First part of ZBI: Burden Interview – Stressors experienced by caregiver

I obtained permission from the authors to make use of the Zarit Burden Interview (ZBI). Chronbach's alpha scores for the ZBI range from .88 to .91, with a test-retest reliability score of .71. The first part, the Burden Interview, was designed to assess

the stressors experienced by caregivers of older people as well as disabled persons (Zarit & Zarit, 1990). The ZBI is widely used worldwide and is cited in many research studies.

5.5.1.2 Second part of ZBI: Memory and Behaviour Problems Checklist

The second part of the ZBI consists of a Memory and Behaviour Problems Checklist, which compares caregiver reaction ratings with frequency ratings of memory and behavioural problems experienced by the ADp. This is an indication of the cognitive status of the patient (Zarit & Zarit, 1990). With regard to reliability, the Guttman split-half reliability coefficient for the frequency of problems on the Memory and Behaviour Problems Checklist was found to be .65, while distress ratings have a split-half reliability of .66, with a test-re-test reliability of .80 for the frequency and .56 for the distress measure (Zarit & Zarit, 1990).

The purpose of The Memory and Behaviour Problems Checklist is to determine how frequently a dementia patient engages in problematic behaviours, and which problems are most upsetting for family members. The Memory and Behaviour Problems Checklist consists of two parts, the first of which determines the frequency with which common problems occur. The time frame used is one week, as this period minimises the recall tasks for informants. The second part examines the informant's subjective appraisal of each problem (Zarit & Zarit, 1990).

The frequency of problems was scored by adding the frequency ratings of the individual items. It is stressed that this instrument provides an estimate of current behavioural and cognitive disruption, and not an indication of the severity of dementia. In summing the reactions a measure is derived of the degree of difficulty caregivers experience in coping with dementia-related problems. Items that are rated as 3 (very much) or 4 (extremely) suggests problems that are particularly troublesome for a caregiver. The sum of the reactions provides an indication of how distressed caregivers are regarding these behavioural problems. Another way to represent this dimension is to compute the mean distress (sum of reactions scores/number of behaviour problems reported), and the cross-products score (frequency x reaction). The latter has been found to be a strong predictor of caregiver burden (Zarit & Zarit, 1990).

5.5.2 The Beck Depression Inventory (BDI/BDI-II)

The BDI/BDI-II was used to measure depression in ADp caregivers. The test-retest reliability reported for a variety of subject groups with this scale range between .74 and .93, while validity coefficients in clinical ratings are .66 (Lezak, Howieson, Loring, Hannay & Fischer, 2004).

The BDI scale consists of 21 groups of statements, where higher scores indicate a greater degree of depression. The severity of the depression is classified as minimal ≤ 13 , mild = 14-19, moderate = 20-28 and severe ≥ 29 .

5.5.3 Personal Resource Questionnaire (PRQ85)

Social support was measured by means of the Personal Resource Questionnaire (PRQ85), developed by Weinert and Brandt (2004). The questionnaire is divided into two parts. Part 1 consists of 10 life situation questions designed to gather information about the person's resources as well as the satisfaction with the resources. This section gives an indication of the person's social network. Part 2 consists of items that explore the following dimensions:

- a) that one is valued (Worth)
 - b) that one is an integral part of a group (Social Integration)
 - c) the provision of attachment/intimacy (Intimacy)
 - d) the opportunity for nurturance (Nurturance) and
 - e) the availability of information, emotional, and material help (Assistance)
- (<http://www.montana.edu/cweinert/instruments/PRQ85/PRQ85.html>).

Part 2 is a 25-item scale based on the five dimensions of support listed above. Each item's response is scored on a 7-point Likert scale with scores ranging from 25 to 175, with higher scores indicating higher levels of perceived social support (<http://www.montana.edu/cweinert/instruments/PRQ85/PRQ85.html>).

The alpha reliability of Part 2 has been determined to be around .90 (<http://www.montana.edu/cweinert/instruments/PRQ85/PRQ85.html>). Consent was obtained from Dr Clarann Weinert to use this scale for the research.

5.5.4 The UCLA Loneliness Scale

The UCLA Loneliness Scale was used to measure ADp caregiver levels of loneliness. This is a widely used measuring instrument (Park, 2004). Reliability for

Version 3 of this scale seems to be very high, with a co-efficient alpha of between .89 and .94 across samples (Russell, 1996).

The new version of the UCLA Loneliness Scale consists of eleven negatively-worded (lonely) and nine positively-worded (non-lonely) items. Scoring requires that items that are asterisked are reversed (i.e., 1=4, 2=3, 3=2, 4=1), after which the scores for each item added. The asterisked items are items 1, 5, 6, 9, 10, 15, 16, 19, and 20. This scale is scored on a Likert scale from 1 (never) to 4 (often), with the total score ranging from 20 to 80 (with higher scores indicating greater loneliness). The Cronbach alpha for this scale ranges between .89 and .94 (Russell, 1996).

5.5.5 Biographical questionnaire

A biographical questionnaire was included, eliciting information on caregiver characteristics such as age, gender, relationship to patient, duration of caregiving, employment status, contact hours with patient per day, highest educational qualifications, psychological or psychiatric illnesses prior to caregiving as well as questions regarding relevant patient characteristics. Burns (2000) states that the degree of cognitive impairment, amount of help required with ADL, personality changes, the presence of psychiatric symptoms and behavioural disturbances that the ADp has can adversely impact on the burden and social isolation experienced by the caregiver. Caregiver characteristics that may affect perception of burden include personality, gender, degree of social support, physical and mental health as well as coping style and expressed emotion.

5.6 Procedure

Self-administered questionnaires were supplied to facilitators of support groups, neurologists, and institutions that deal with the older people for distribution amongst caregivers who complied with the inclusion criteria. In some instances, individual caregivers were approached directly, and some questionnaires were posted to participants together with a prepaid response envelope.

A total of 40 caregivers of dementia patients, of whom the majority were ADps, completed the self-administered questionnaires. Most of the participants were recruited via AD caregiver support groups associated with Alzheimer's South

Africa, and neurologists; although some were approached directly. The instruments administered were the UCLA Loneliness Scale, Beck's Depression Inventory, Zarit Burden Interview and Memory and Behaviour Problems Checklist, Personal Resource Questionnaire (PRQ85), as well as a biographical questionnaire eliciting caregiver and patient characteristics.

Only caregivers who were personally responsible for the care of a patient, such as spouse, child or nurse were considered for participation. Of the 40 participants, 34 were living with the patient, while six had contact with the patient on a daily basis. The participants were heterogeneous and consisted of 12 male and 28 female caregivers. Completing the questionnaires took approximately 30 – 40 minutes.

5.7 Data Analysis

The researcher coded all the questionnaires and the data was captured by the Department of Statistics at the University of Pretoria, who also performed the statistical analyses for the quantitative aspects of the data. A small qualitative analysis was included in certain sections, such as Part 1 of the Personal Resource Questionnaire and the Burden Interview: Unassigned Items.

5.7.1 Descriptive analysis

Descriptive statistics were used to indicate caregiver and patient characteristics of the sample group. Constructs such as the mean and standard deviation (SD) were calculated while the frequencies were tabled.

5.7.2 Correlational analyses

Correlational analyses were used for some of the data and were portrayed by means of correlation matrices. The Pearson's r was used as a correlation coefficient that reflects the degree to which mutual relations between X and Y exist. Thus a positive r means that an increase in X is associated with an increase in Y , whereas a negative r means that an increase in X is associated with a decrease in Y . The Pearson r correlation coefficient is also known as the basic measure of association (Rosnow & Rosenthal, 1999). DiMatteo and Martin (2002) state that although correlational studies do not allow the researcher to draw causal connections between variables under study, correlational studies have value in that they determine whether two variables are related, thus whether they covary. The

possibility of causality may sometimes be entertained where one variable precedes another in time, and is therefore more likely a cause than an effect.

5.7.3 Between-group comparisons

In order to determine the between group comparisons and analysis of variance (ANOVA) was used. The ANOVA test is a parametric statistic (Cohen, Manion & Morrison, 2003). Rosnow and Rosenthal (1999, pg. 324) explain that “the *F* test used in a between-conditions ANOVA is a ratio of the spread of mean scores around the grand mean to the spread of scores within each condition”.

5.8 Research Questions and Conclusion

The following research questions were investigated:

- a) What is the relationship between depression, loneliness, burden of care and real and/or perceived social support?
- b) What is the relationship between psychological health status and caregiver characteristics?
- c) What is the relationship between psychological health status and patient characteristics?

In the next chapter the research results are discussed in detail, with the different research questions forming the basis of these discussions.

CHAPTER 6

RESEARCH RESULTS

In this chapter the results of the statistical analysis are outlined in the following order:

- (a) biographical characteristics of both the caregivers and patients of the sample group
- (b) Beck's depression scale
- (c) The Burden Interview by Zarit and Zarit and the Memory and Behaviour Problems Checklist
- (d) UCLA Loneliness scale
- (e) Personal Resource Questionnaire PRQ85 measuring social support

6.1 Biographical Information

Descriptive statistics were used to analyse the biographical characteristics of the sample. The biographical characteristics of the caregivers in the sample are presented in table 1.

Table 1: Biographical characteristics of caregivers

Biographical variables	Frequency
Caregiver relationship to patient	
Spouse	28
Child and other	12
Gender	
Male	12
Female	28
Highest educational qualifications	
Primary and secondary	14
Tertiary	26
Member of a support group	
Yes	32
No	8

Caregiver variables that are of some significance are the following:

- (a) Twenty-eight spouses and twelve children comprised the sample of caregivers. This corresponds to research that indicates that spouses are the primary caregiver for ADps (Murray & McDaid, 2002).
- (b) The majority of carers were female. This supports Fernandez-Ballesteros's (2003) indication that the average profile of a caregiver at risk is a middle-aged or older woman who lives with the care recipient.
- (c) In the caregiver group, at least 26 caregivers had tertiary educational qualifications in relation to 14 who had only secondary educational qualifications.

The average age of the caregivers in this study was 64,6 years, and 32 people (80%) were members of a support group. Of the sample, nine caregivers were employed in comparison to 30 who were unemployed. The average duration of the caregiving process was 4,7 years.

The biographical characteristics of patients in the sample are outlined in table 2.

Table 2: Biographical characteristics of patients

Biographical variables		Frequency
Gender	Male	18
	Female	22
Highest educational qualifications	Primary and secondary	34
	Tertiary	6
Diagnosis confirmed by	Neurologists	24
	Psychiatrists	6
	GPs and other	10

Significant patient variables include the following:

- (a) Eighteen male and 22 female patients participated in the study.
- (b) The patients ranged between 57 and 96 years, with an average age of approximately 74 years. The patients' age range was as follows: 3 were between 51-60 years; 7 were between 61-70 years; 22 were between 71-80 years, six were between 81-90 years, and 1 was over 90 years old.
- (c) The diagnosis was confirmed most often by a neurologist (24 patients) and least often by a general practitioner.
- (d) The form of dementia was as follows: 33 patients were diagnosed with Alzheimer's disease, 3 with Vascular Dementia, 2 with Pick's disease and 1 with Alzheimer's Parkinson's Dementia.
- (e) The average duration of the illness was approximately 5,1 years.

6.2 Beck Depression Scale

The mean score for the BDI-II of this study group was 16.13 and the SD 8.82. Twenty-three respondents (72%) scored 19 or below on the scale, which places them on the low end of the depression scale. Of these 23, fourteen were classified

as having minimal symptoms of depression and nine as having mild symptoms. Six respondents (19%) reported moderate symptoms and the remaining three (9%) reported symptoms that could be classified as severe depression.

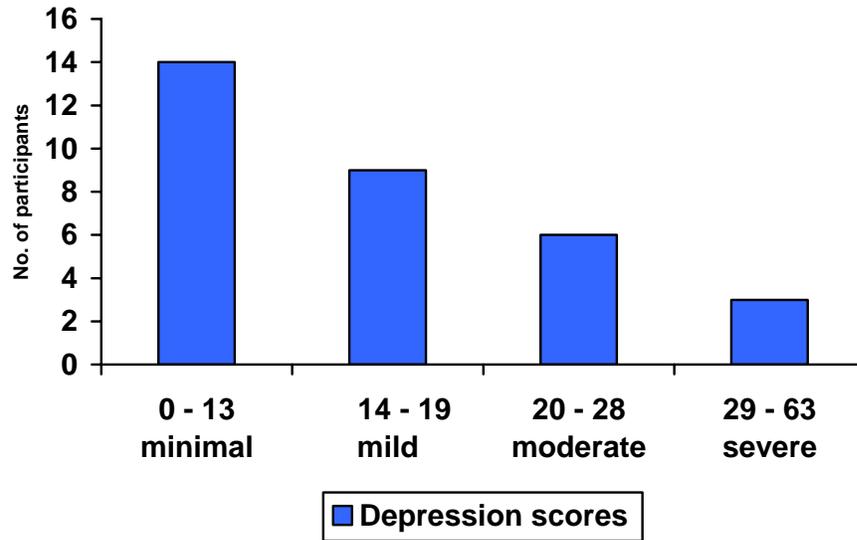


Figure 2: BDI Scores

To determine if depression was associated with caregiver and patient variables an ANOVA test was conducted.

Table 3 : Between-group comparisons and Depression (ANOVA)

	p-values with patient age ac	p-values with relationship ac	p-value with illness duration ac	p-value with care-giver age ac	p-value care-giver gender ac	p-value with care-giver educational qualification ac	p-value with duration of care-giving ac	p-value with patient gender ac
Depression	0,0277*	0.2123	0.7761	0.4106	0.7757	0.7627	0.5571	0.7328

$p \leq 0,05$

as covariate (ac)

The Post Hoc test (also known as the Duncan test or Duncan's multiple range test) indicated that the BDI score was higher for the caregivers with patients in the two age groups of 51-70 and 71-80 when compared with the groups aged 81 or more.

6.3 Memory and Behaviour Problems Checklist and the Burden Interview by Zarit and Zarit

6.3.1 The Burden Interview

This measuring instrument was used to establish whether

- (a) the burden (role and personal strain) experienced by caregivers correlates significantly with depression
- (b) the frequency of behavioural problems correlates with caregiver burden
- (c) caregiver reaction ratings correlate with frequency ratings of memory and behavioural problems

The Burden Interview is scored by adding the responses of the individual items, with higher scores indicating greater caregiver distress. Two scales have been derived from The Burden Interview by using confirmatory factor analysis, and represent the dimensions of Personal Strain and Role Strain (Zarit & Zarit, 1990).

Table 4: Pearson correlations of Personal Strain and Role Strain with Depression, summary of frequencies and summary of reactions

Variables	Personal Strain	Role Strain
Depression (Beck's Depression Inventory (BDI))	0.473* 0.0082	0.500* 0.0049
Summary frequencies (Frequency of behavioural problems)	0.407* 0.0430	0.427* 0.0330
Summary of reactions (Reaction on behavioural problems)	0.318 0.1384	0.382 0.0719
Cross-products (frequency x reaction)	0.32063 0.1358	0.40204 0.0572

$p \leq 0,05$

The above table clearly indicates that a significant positive correlation exists between personal and role strain and depression. Moreover, a significant

correlation exists between the frequencies (the ratings of how frequent memory and behavioural problems occur) and personal and role strain, where the latter, together with the summary of frequencies, represents the burden experienced by the caregiver.

Furthermore, there is a significant relationship between personal strain and level of education, where the tertiary education group experiences greater strain than the primary and secondary educational group. This is indicated in the following table:

Table 5 : Between-group comparisons and Personal Strain (ANOVA)

	p-values with patient age ac	p-values with relationship ac	p-value with illness duration ac	p-value with caregiver age ac	p-value caregiver gender ac	p-value with caregiver educational qualification ac	p-value with duration of caregiving ac	p-value with patient gender ac
Personal Strain	0.1632	0.8105	0.0619	0.7084	0.7394	0.0355*	0.0641	0.1632

$p \leq 0,05$

* as covariate (ac)

The Post Hoc test (Duncan test) indicates that the score on the Personal Strain scale is higher for the caregivers with tertiary educational qualifications than for caregivers with primary and secondary qualifications. In addition, Role Strain has a statistically significant relationship with higher educational level ($p = 0.0287$), suggesting that the higher educational group experiences more role strain than the primary and secondary educational group.

6.3.2 The Memory and Behaviour Problems Checklist

The Memory and Behaviour Problems Checklist consists of two parts, where the first part determines the frequency with which common problems have occurred and the second part obtains the informant's subjective appraisal of each problem. In adding the reactions a measure is derived of the degree of difficulty caregivers experience with dementia-related problems (Zarit & Zarit, 1990).

A significant negative correlation exists between the sum of the reactions and duration of caregiving as indicated by $r = -0.417$ ($p = 0.0339$). This suggests that as the period of caregiving increases, caregivers report fewer problems. This may

be because caregivers become accustomed to the behaviours or become desensitised towards them.

6.4 UCLA Loneliness Scale

Classification of UCLA Loneliness Scale ranges from 20 (lowest loneliness) to 80 (highest loneliness).

The mean score for the UCLA Loneliness Scale for this sample was 45.13 with a SD of 11.89. The minimum score for the respondents was 24 with a maximum of 74. Of these respondents, 57% scored in the lower half of the measuring scale and 43% on the higher half, with a means score of 45 out of a possible 80. This suggests that most participants are moderately lonely.

The most relevant findings of the study with regard to loneliness are tabulated below:

Table 6: Pearson correlations of UCLA Loneliness Scale with Personal Strain, Role Strain, Depression and Social Support

Variables	Loneliness UCLA
Personal Strain	0.420* 0.0118
Role Strain	0.322* 0.0552
Depression	0.551* 0.0013
Perceived Social Support (PRQ85 – 2 nd part)	-0.507* 0.0036

$p \leq 0,05$

The above table indicates a significant positive correlation between Loneliness and Personal Strain with $r = 0.420$ ($p = 0.0118$). Loneliness and Depression are also significantly correlated with $r = 0.551$. Beeson et al. (2000) state that the more loneliness caregivers experience, the more depressed they become. This finding is supported by later research by Beeson (2003), who reported that loneliness was the only predictive variable for AD caregiver depression.

The significant negative correlation between loneliness and perceived social support (PRQ85 – 2nd part) where $r = -0.507$ ($p = 0.0036$) confirms other research findings that an increase in social support decreases feelings of loneliness and vice versa. Tebb and Jivanjee (2004) believe that health care officials should be alerted to the isolating effects of caregiving and the serious biophysical, psycho-emotional, social and economic impact that it has on caregivers' health.

6.5 Personal Resource Questionnaire PRQ85 – Weinert and Brandt

6.5.1 Part 2 of the Personal Resource Questionnaire PRQ85

Part 2 of the questionnaire: “Perceived Social Support”.

This questionnaire is described as follows:

“The five hypothesised underlying dimensions were: a) the indication that one is valued (Worth), b) that one is an integral part of a group (Social Integration), c) the provision for attachment/intimacy (Intimacy), d) the opportunity for nurturance (Nurturance), and e) the availability of information, emotional, and material help (Assistance)” (<http://www.montana.edu/cweinert/instruments/PRQ85/PRQ85.html>). We are looking at five composite scores (thus a score on each dimension).

Part 2 thus measures perceived social support. The statistical analysis sought to establish the correlations between:

- Burden and Perceived Social Support
- Loneliness and Perceived Social Support
- Depression and Perceived Social support

The results indicate a significant negative correlation between Perceived Social Support and Loneliness with r at -0.507 ($p = 0.0036$). This strongly suggests that perceived social support is a significant predictor of caregiver loneliness. The negative correlation between Loneliness and Perceived Social Support confirms other research findings that increased social support decreases feelings of loneliness and vice versa. The lack of perceived social support can escalate into loneliness, which may further contribute to depression amongst caregivers. In

support of this, a significant positive correlation was found between Loneliness and Depression, where $r = 0.551$ ($p = 0,0013$).

In addition, perceived social support shows a significant correlation with loneliness, while loneliness significantly correlates with role and personal strain (burden). It can thus be assumed that a significant correlation exists between perceived social support and caregiver burden. The main effect hypothesis suggests that social support in itself is beneficial and that the absence of this can be stressful, thus indicating that social support mediates the stress-illness link (Ogden, 2004).

6.6 Summary of Results

Table 7: Correlations between variables

Variable	PSS*	D	Burden		
			RS	PS	Sum Freq Crosstab
Loneliness (L)	-0.507 0.0036	0.551 0.0013	NS	0.421 0.0118	NS
Depression (D)	NS	NS	0.500 0.0049	0.474 0.0082	NS
Summary of Frequencies	NS	NS	0.428 0.0330	0.408 0.0430	NS
Duration of caregiving	NS	NS	NS	NS	-0.417 0.0339

$p \leq 0,05$

* The second part of the Social Support Questionnaire measures perceived social support

6.6.1 Research questions

In the following section, the research questions posed in chapter 1 are answered in accordance with the study findings.

(a) What is the relationship between depression, loneliness, burden of care and real and/or perceived social support?

- There is a significant positive correlation between loneliness and depression ($r = 0.551$).

- There is a significant negative correlation between perceived social support and loneliness ($r=-0.507$).
- There is a significant positive correlation between loneliness and personal strain (burden) ($r = 0.421$).
- There is a significant positive correlation between both role and personal strain (burden) and depression ($r = 0.500$) and ($r = 0.473$).

(b) What is the relationship between psychological health status and caregiver characteristics?

The results indicate that participants with higher educational qualifications experience more personal strain and role strain (burden) than those with a primary or secondary qualification, with $p = 0.0355$ and 0.0287 respectively.

(c) What is the relationship between psychological health status and patient characteristics?

- Patient age correlates significantly with depression.
- There is a significant correlation between summary of frequencies (frequency of behavioural problems) and personal and role strain, as both show a significant positive correlation with the frequencies of behavioural problems of the patient ($r = 0.408$ and $r = 0.428$ respectively). The latter findings indicate a significant correlation between the cognitive status of the patient and caregiver burden.

An interesting finding is the significant negative correlation between the sum of the reactions and duration of caregiving ($r = -0.417$), which suggests that as the period of caregiving increases, the caregiver reports fewer frequencies of problems. As mentioned elsewhere, this may be because caregivers become used to the behaviour or become desensitised towards the behavioural problems to the extent that they have little or no effect on caregivers.

The Post Hoc test (Duncan test) showed that the BDI score was higher for the caregivers of patients in the age groups of 51-70 and 71-80 compared to the 81+ age group. This may be because people expect the very old to show some cognitive and physical decline, and so this does not have as great an effect on caregiver depression as similar impairments in younger patients. Also, it could be that people do not expect to find the behavioural and other problems associated with AD in people in the younger age groups, and so these problems are far more disturbing and emotionally upsetting for caregivers.

Another interesting finding is that participants with higher educational qualifications experience more personal strain and role strain (burden) than those with primary or secondary schooling. This could be because people with higher educational qualifications may feel the need for more social interaction and stimulation.

6.6.2 Qualitative research results

6.6.2.1 Burden Interview: Unassigned Items

Four out of the 22 questions on the Burden Interview were unassigned (items 7, 10, 15 and 22). The results of these items are reported below:

“Item 7. Are you afraid of what the future holds for your relative?”

Fourteen participants (35%) indicated they are nearly always afraid of what the future holds for their relative, eleven (27.5%) are sometimes afraid and seven (17,5%) are afraid quite frequently.

“Item 10. Do you feel your health has suffered because of your involvement with your relative?”

Only five participants indicated that their health had never been affected, six rarely, seventeen sometimes, five quite frequently and five nearly always.

It seems that caregivers generally feel that their health has suffered as a result of their involvement with caring for a relative.

“Item 15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?”

Fifteen participants indicated that they were never concerned about financial strain, four rarely, ten sometimes, five quite frequently and three nearly always.

These findings indicate a moderate degree of concern amongst caregivers with regard to the financial burden of caregiving.

“Item 22. Overall, how burdened do you feel in caring for your relative?”

With regard to the burden felt by the caregivers, one indicated no burden at all, eight indicated a little, seven a moderate degree, fifteen felt substantially burdened and eight felt extremely burdened.

These findings suggest that caregivers feel moderately to severely burdened by their caregiving task.

The above findings show that the participant caregivers feel concerned about what the future hold for their patients. There is also a feeling amongst the participants that their health has suffered due to their caregiving responsibilities. The caregivers also feel burdened by their caregiving task.

6.6.2.2 Part 1 of the Personal Resource Questionnaire PRQ85

Part 1 consists of ten life situations in which a person might need assistance, and is designed to gather information about participants’ resources, their degree of satisfaction with life, and whether or not any of these situations occurred during the previous six months of the participant’s life. Findings on this measure provide an indication of the quality and extent of an individual’s social network (<http://www.montana.edu/cweinert/instruments/PRQ85/PRQ85.html>). The results of this measure are discussed below:

“Question Q1a-1. If you experience urgent needs (crisis) who would you turn to for help?”

Of the 40, 22 participants indicated that they would turn to their child(ren) for help, 14 indicated that they would turn to a relative or family member, 13 would approach a friend, and 10 indicated that they would make use of a spiritual advisor (minister, priest, etc.). Only four people indicated that they would turn to a professional (nurse, counsellor, social, worker, employer, etc.). Such urgent needs had been experienced by 19 people during the past six months, of which 36% were fairly satisfied with the help they received and 40% very satisfied.

“Question Q2A. If you need help for an extended period of time in caring for a family member who is sick or handicapped, who would you turn to for help?”

Fifteen participants replied that they would turn to their child(ren) for help, 15 would approach a family member for assistance, and 15 would make use of a professional. Thirteen participants had needed help during the past six months. Of these, 41% were fairly satisfied and 35% were very satisfied.

“Question 4A. If you need help or advice for a problem with regard to a family member or friend, who would you turn to for help?”

Of the sample, 18 participants indicated that they would turn to their child(ren) for help, 12 would go to a relative or family member, 16 to a friend, eight would approach a spiritual advisor, 10 would make use of a professional and five would attend a self-help group. At least 12 of the respondents had needed assistance in the last six months, with 53% being fairly satisfied and 24% very satisfied.

“Question 9A. If you are having problems with your work at home or at your place of employment, who would you turn to for help?”

Ten participants indicated that they would turn to their child(ren), 15 indicated that they would turn to a friend for help, eight to a spouse, partner or significant other, eight would approach a relative or family member, six would see a professional, and four would attend a self-help group.

“Question 10A. If you need someone to talk to about your day-to-day personal concerns, who would you turn to for help?”

Half of the respondents (20) would talk to their children, nine to their spouse, partner or significant other, 16 to a relative or family member and 23 to a friend. Of those 31 respondents who had needed such help, 34% indicated that they were fairly satisfied while at least 40% indicated that they were very satisfied. This finding suggests that in some instances, the help of a friend can be of great value, although caregivers most often rely on the assistance of their child(ren).

From the above it is evident that children play the most important supportive role in the caregiver's life, followed by family and friends. Spiritual leaders and professionals play a lesser yet also important role. Caregivers seem to be fairly satisfied with the support that they had received over the previous six months.

6.7 Conclusion

The research aimed to investigate whether correlations exist between loneliness, depression, burden and perceived social support. The results show significant correlations for all the relationships investigated. In addition, it was found that caregiver and patient characteristics significantly impact on some of the variables. The results of this research confirm the findings of many previous research studies.

Furthermore, despite the fact that each caring situation is unique and each patient at a different stage of the disease, the participant caregivers displayed remarkable similarities, as indicated by the significance of the results. The findings demonstrate the complexity and far-reaching consequences of the illness that the AD caregiver has to cope with. Larrimore (2003) emphasised that caring for AD patients can have a significant impact on the psychological health of the caregiver. However, the results demonstrate that social support can have a mediating effect on psychological health.

This study's investigation of the relationship between social support and psychological health (depression, loneliness, and perceived burden of care) amongst a cohort of Alzheimer's caregivers confirms previous research that caring for the ADp is often an emotionally exhausting task with far-reaching consequences for the psychological health of the caregiver. Furthermore, perceived social support impacts positively on caregivers' psychological well-being.

The following chapter discusses and summarises the significant results with regards to depression, loneliness, burden of care, psychological health status of caregiver as well as caregiver and patient characteristics. Social support and the psychological health status of the AD caregiver, as well as caregiver satisfaction with social support resources and burden of care, is also addressed. The chapter concludes with a reflection on caregiving and intervention strategies for AD, limitations of the study, and recommendations for future research.

CHAPTER 7

DISCUSSION

Various studies state that due to increased longevity, ageing-related illnesses such as AD have become a major health care problem. Furthermore, ADp caregivers are confronted with an illness that has far-reaching consequences for both caregiver and patient (Thies, 2004; Thomson et al., 2007). The current study highlights results from previous studies that reveal the tremendous psychological health implications of caring for an ADp. This study investigated the impact of social support on variables such as loneliness, depression and burden of care, and looked at the effects of these relationships on the psychological health of the AD caregiver. The characteristics of both patients and caregivers were also included as it is evident from other research studies that these may also predict outcomes in psychological health of AD caregivers.

The findings of this study show a negative correlation between perceived social support and loneliness. This suggests that caregivers need additional support to curb feelings of loneliness. Further findings are that a positive relationship exists between personal strain (burden) and loneliness, and between depression and loneliness. This finding echoes the results of other studies, confirming that this vulnerable group is more prone to depression than a comparative group of non-caregivers.

There is substantial evidence to suggest that both morbidity and mortality are much higher amongst caregivers than among non-caregivers of the same age (DiMatteo & Martin, 2002; Ogden, 2004). The failure of most countries to provide adequate assistance to ADp caregivers has tremendous implications and risks for caregivers' psychological health, to the point that caregivers themselves may become patients. This can cripple the caregiving task, which is mostly rendered by individual family members. Since caregivers function to alleviate the responsibility of the community at large, they deserve to be assisted in their caregiving task for the benefit of the greater society.

In most countries assistance to the caregivers are inadequate. In South Africa caregivers receive little or no assistance, placing caregivers under tremendous pressure. Caregivers are at risk as many of them are themselves older people with failing health. It is thus of the utmost importance that cognisance be taken of the results of the research to enable the responsible parties to address the problems and risks associated with caregiving.

Research worldwide clearly indicates that caring for dementia patients is a growing concern as millions of people all over the world are confronted by this devastating illness. This problem will grow together with increased longevity and expanding population sizes. This illness not only affects patients, but caregivers' lives are also disrupted to the extent that caregiving may become a full-time career. In discussing the findings of this study, this chapter reflects on caregiving and intervention strategies for the AD caregiver.

7.1 Depression, Loneliness, and Burden of Care

In an extensive study of 4 278 people aged 75 years and above, including 783 caregivers (18% of the sample), the researchers found that loneliness was the most important factor to predict low quality of life among caregivers as well as older people in general (Ekwall et al., 2005). In another study by Beeson (2003) that was conducted with 49 AD caregiving spouses, significantly higher levels of loneliness and depression were reported amongst the AD caregiving group than among the 52 non-caregiving spouses who also participated in the study. In a study on 34 female Italian Alzheimers' caregivers undertaken over a total of 816 caregiving days, it was found that there was a positive correlation between hours of care and depression scores as well as physical and psychological illness scores (Sansoni et al., 2004). Goodman's (2000) study indicated that poor caregiver health, patient behavioural problems as well as caregivers' reaction to the problematic behaviour were factors most strongly associated with caregiver burden.

The current study confirms previous research in finding that caregivers feel isolated in their caregiving task. This is indicated by a significant positive correlation between loneliness and depression. There is also a significant positive correlation between loneliness and personal strain (burden), suggesting, in line with other

studies, that loneliness can have an influence on the burden experienced by ADp caregivers.

Furthermore, the results show a significant positive correlation between personal and role strain (burden) and depression. In a study by Danhauer et al. (2004), the researchers confirmed that caregiver depressive symptoms were associated with behavioural disturbances, and that the effect could primarily be attributed to aggressive behaviours of the patient. Clyburn et al. (2000) found that higher frequencies of disturbing behaviour, low informal support as well as a community-dwelling patient were associated with burden, which commonly escalated into depression amongst caregivers.

7.2 Psychological Health Status, Caregiver Characteristics and Patient Characteristics

The findings reveal a significant positive correlation between the frequencies of problematic symptoms (these are the ratings of how frequently memory and behavioural problems occur, which provides an indication of the patient's cognitive abilities) and personal and role strain, where role and personal strain as well as the sum of the frequencies represent caregiver burden. In this respect, a significant correlation was found between the cognitive status of the patient and burden experienced by the caregiver. Clyburn et al.'s (2000) research, cited in the previous section, again confirms these findings: high frequencies of disturbing patient behaviour, caring for an indwelling patient, and low informal support were all related to higher caregiver burden, and consequently to more depressive symptomatology in the caregiver.

In the current study, the age of the patient was found to correlate significantly with caregiver depression. The BDI rating was found to be higher for caregivers of younger patients (in the two groups of patients aged 51-70 and 71-80) than for caregivers of patients aged 81 and older. As mentioned elsewhere, it is likely that people expect much older people to show some cognitive and physical decline, and as such it has a lesser effect on the caregiver's depressive emotions than when patients younger than 80 show similar decline. Correspondingly, it is possible that people do not expect to find the behavioural and other problems associated with AD in relatively younger people, and so these symptoms could be far more

disturbing and emotionally upsetting for caregivers of relatively younger patients. The question is whether cognitive and physical decline is more readily accepted for the very elderly compared to younger patients.

7.3 Social Support and Psychological Health Status

A significant negative correlation was found between loneliness and perceived social support. This confirms that an increase in social support diminishes loneliness. Correspondingly, a lack of perceived social support could escalate into loneliness during the caregiving process. These findings are especially relevant for support groups, authorities and institutions involved with caregiving activities.

The significant negative correlation between loneliness and perceived social support is upheld by the significant positive correlation found between loneliness and personal strain (burden). This implies that social support (in this instance perceived social support) can have an effect on the burden experienced by ADp caregivers. A significant positive correlation was also found between both role and personal strain (burden) and depression. These results indicate that while there is a correlation between loneliness and perceived social support, loneliness and burden as well as burden and depression, perceived social support can mitigate the loneliness, depression and burden experienced by caregivers. Larrimore (2003) points out that the long-term task of caregiving is associated with increased risk of physical and mental health problems such as depression, social isolation and many others; while Chappell and Reid (2002) found that perceived social support is strongly related to well-being, but unrelated to burden. These findings suggest that caregivers' quality of life can be improved even with burden in their lives, and that a focus on burden should be supplemented with an emphasis on quality of life.

7.4 Caregiver Satisfaction with Social Support Resources and Burden of Care

Part 1 of the Personal Resource Questionnaire (PRQ85) investigated the needs of the caregiver with regard to assistance as well as personal resources. This section

also endeavoured to ascertain to what degree the participant caregiver was satisfied with these resources, and whether or not any of these situations had occurred during the past six months. The aim of this exercise was to obtain an indication of the caregiver's social support network. The results show that in many instances the help of friends, family, and professionals can be of great value, and that in most instances caregivers rely a great deal on assistance from their children. Indeed, this study found that children play the most important supportive role in the caregiver's life, followed by family and friends, and thereafter spiritual leaders and professionals. The participants seemed fairly satisfied with the support they had received over the previous six months. This contrasts with Ferrario et al.'s (1999) finding that only 45% of caregivers felt supported by other relatives, and received satisfactory support from them when assistance was needed. These authors found that at least 23% of the sample group received no assistance from relatives and at least 16% did not expect to receive assistance even if needed. Mittelman (2002) reported that more caregiving husbands than caregiving wives reported few or no friends, although more caregiver husbands than wives received help from their adult children, especially their daughters.

The Burden Interview Unassigned Items indicated that the caregivers feel concerned about what the future holds for their patients. They also reported that their health has suffered due to their caregiving responsibilities. From these unassigned items it is apparent that caregivers feel burdened by their caregiving task. This finding is echoed by Bell et al. (2001) who found that the burden experienced by caregivers of ADps has an effect on their overall health-related quality of life.

In Part 2 of the Personal Resource Questionnaire (PRQ85), which measures "Perceived Social Support," a significant negative correlation was found between perceived social support and loneliness. This confirms research that states that social support has an impact on loneliness, which can further escalate into depression and increased burden amongst ADp caregivers.

A significant negative correlation between loneliness and perceived social support exists alongside a significant positive correlation between loneliness and personal strain (burden). This implies that social support (in this instance perceived social support) can affect the burden experienced by caregivers. A significant positive correlation was also found between both role and personal strain (burden) and

depression. These findings suggest that social support can mediate the relationships between caregiver burden, depression and loneliness. Beeson (2003) confirmed that loneliness was a predictive variable for AD caregiver depression, while Chambers et al. (2001) found that coping and social support are resources that influence the extent to which a major stressful situation such as caregiving can impact on psychological well-being. Fernandez-Ballesteros (2003) stresses that while caregiving is burdensome, it is generally accepted that caring for a dementia patient poses one of the greatest challenges.

The implication of the above is that social support can have a mediating effect on the negative psychological consequences of caring for an ADp. This supports reports in the literature that perceived social support and caregiver feelings of loneliness are negatively correlated. Both the current study and the literature show that burden correlates significantly with depression, indicating that loneliness is in part responsible for depression amongst caregivers. The finding that caregiver and patient variables contribute to depression, loneliness and burden has far-reaching implications for interventions by social health authorities, which should focus on providing additional support for caregivers. Potgieter and Heyns (2006) emphasise the vast amount of literature that shows that the social, emotional, behavioural and psychological challenges associated with AD caregiving lead to a high degree of burden amongst ADp caregivers. Jansson et al. (2001) confirm that spousal caregiving is physically demanding, and a contributory cause of the perceived burden that is experienced by many caregivers.

7.5 Reflections on Caregiving and Intervention Strategies for Alzheimer's Disease Caregivers

Olivier and Francoise (2005) state that populations' increased longevity will be accompanied by increases in the frequency of dementia. The prevention of cognitive disorders and dementia poses a major challenge to public health.

Fernandez-Ballesteros (2003) recommends that the needs of caregivers as well as their patients should be structured in such a way that they are addressed as caregiver burden. This author states that this is both an individual and a societal problem. Public policy should address caregiver burden and take cognisance of the buffering effect of social support on psychological health. Furthermore, policies

that make provision for carers should include services that specifically benefit carers, such as domestic and personal care services, breaks from caring as well as patient-directed services (Pickard, 2001). Goodman (2000) suggests that the management of AD interventions for caregivers should focus on caregiver health and patient behavioural problems. Reducing caregiver burden has economic implications for the institutionalisation of ADps and the utilisation of the health care system. Murray and McDaid (2002) add that not only should evaluations of interventions with regard to caregiving consider the impact on formal health and social care resources, but also the effect of burden and resources of family carers. Ferrario et al. (2003) believe that caregiver needs should be identified in order to determine how best to provide them with support that is specific for their situations.

Morano (2003) states that the psychological well-being of caregivers may be improved by empowering them through interventions that focus on how they appraise their situation and their coping skills. Tebb and Jivanjee (2004) agree, stating that resources of support may curb the isolating effect of caregiving that lead to biophysical, psycho-emotional, social and economic effects. It is thus evident from the literature that stressful circumstances around the caregiving of the ADp put tremendous pressure on caregivers, especially when they experience a lack of social support. Lack of support may increase the burden carried by the caregiver, increase feelings of loneliness and result in depressive symptoms. All of the aforementioned have an impact on society as a whole.

Furnish (2002) advocates that mental health policies should incorporate a preventative approach, standards and regulatory mechanisms in tertiary care should be improved and current service solutions should be reappraised and adjusted to address the problems of ADp caregivers. Despite the fact that more and more ADps are being cared for at home, no national policy exists to acknowledge this situation and provide for the development of alternative and more humane dementia services through a strategic approach and comprehensive service model.

According to Tebb and Jivanjee (2004), continued education via the media could raise community-wide awareness of the biophysical, psycho-emotional, social, and economic effects of Alzheimer's disease and its isolating effects on caregivers. Community support can be obtained through existing community organisations as well as church-based communities. In this way, formal and informal support may be

offered to caregivers. Formal services should be available, accessible, appropriate and affordable when needed, and should take the multiple dimensions of caregiver isolation into consideration to reduce isolation and its negative effects on the caring role. Strumpher (2002) agrees that caregivers cannot provide care for the person with dementia (Alzheimer) in isolation, but that a variety of services should be utilised to help families, professional carers and patients to cope with the situation. It is very important for policymakers and social and health professionals to fully understand the implications of the burden of caregiving and the effect it has on the caregiver.

Further research could enhance understanding of the process of isolation and further identify the types of community supports and interventions that could help to curb caregiver isolation (Tebb & Jivanjee, 2004). According to Furnish (2002), dementia services could be delivered by a combination of disciplines involving stakeholders from all social settings. Although there are some clear signs of improvement in the public's general knowledge of dementia, appreciation for the burden carried by the families of dementia patients is limited. Evidence suggests that the burden of care for severely cognitively impaired older people falls more heavily on informal carers than physically frail people with a similar degree of disability, leaving AD caregivers with no or very little assistance from society.

Alzheimer's South Africa (2004) states that there is no specific government policy on dementia. Home-based care is the only option as institutional care is not within the means of most South Africans. Policymakers in the health and social care services are faced with the challenge of providing assistance to caregivers. Should informal caregiving cease, it would place an enormous economic burden on the rest of society. Bosanquet (2001) notes that the total economic cost of AD is enormous; and that providing care to large numbers of older patients with AD places a huge economic burden on healthcare systems. However, caregivers report high levels of psychological and physical health stress due to their caregiving role. Although the care and support of AD patients and their caregivers is not the responsibility of any single professional health agency, it should form part of an integral care system provided by a number of agencies.

Zarit and Leitsch (2001) state that the unique nature of AD requires intervention programmes to assist caregivers and patients to be flexible to accommodate the degenerative course of the disease and the unique strain experienced by family

caregivers. The purpose of this study was to explore the relationship between psychological health status and perceived social support. Knowledge about, information on and awareness of this relationship helps us to understand the factors associated with the health and well-being of the AD caregiver.

7.6 Conclusion

AD is increasingly being recognised as a major health care challenge due the increasing longevity of populations (Bosanquet, 2001). At the same time, considerable financial, social and emotional costs are associated with caring for ADps at home. Clark and Cummings (2004) warn that unless preventative measures are found to prevent or delay the onset of AD, a large segment of the population over 65 years old will develop dementia. This will not only cause a tremendous social and economic burden, but will also be tragic and challenging for families. While patients are robbed of their identity, family bereavement may begin from the onset and diagnosis of the illness. While family caregivers are the main contributors to the caregiving process they also have to deal with the emotional, practical and economic strain that accompany the illness. According to Tebb and Jivanjee (2004), although there has been an increase in public awareness of the implications of Alzheimer's disease since Fengler and Goodrich (in Tebb & Jivanjee, 2004) termed the caregiver as the "the hidden patient," many communities do not have supportive interventions available to Alzheimer's patients and their caregivers.

The aim of this study was to investigate whether correlations exist between the different variables, namely, loneliness, depression, burden and perceived social support. The results show significant relationships between all the variables. In addition, it was found that caregiver and patient characteristics significantly impacted on some of the variables. The results of this research replicate the findings of many previous research studies.

The results of this study could be used to inform caregiver support groups as well as other organisations involved in the caregiving task. Application of the findings may contribute to increasing the quality of life and well-being of both caregivers and Alzheimer's patients. Due to the rapid increase in the number of dementia patients worldwide, it is of the utmost importance that health professionals, especially those

involved with the planning of current and future healthcare service provision, fully consider all sources (and especially informal sources) of potential assistance in managing this illness (Bosanquet, 2001). Chambers et al. (2001) point out that current community policies and health care depend largely upon the informal home care system. Despite the vast contributions carers render to society, research evidence suggests that their needs are not properly addressed.

7.7 Limitations of the Study

Due to the size of the sample and the fact that only a small portion of the caregiving fraternity could be accessed, the results might not be representative of the larger caregiving group. However, the results should give an indication of what could be expected from a larger and more representative research sample.

Some of the caregivers may have been daunted by the length of the questionnaires. This may be relevant for those caregivers who themselves are older and experience some cognitive decline associated with the normal ageing process. Some caregivers admitted that they were under too much stress from their caregiving responsibilities and could not participate as it would add to their overload. It may be surmised, therefore, that some participants' answers may have been affected by fatigue.

Since the majority of the participants (80%) were recruited through caregiver support groups, it is likely that they already received some support. Participants who do not form part of such groups may feel more socially alienated, which would impact negatively on their emotional well-being. According to theory and empirical research on life-course transitions and social support, support from an experientially similar peer (a person who has experienced the same stressful transition) promotes positive psychological outcomes (Pillemer & Suitor, 2002). Thus, had a sample been recruited from the population of caregivers who do not receive such support, the results may have been different. In Pillemer's and Suitor's (2002) study, the researchers found that the level of interactions had a modest buffering effect for persons who experienced more stressful caregiving situations. Potgieter and Heyns (2006), who conducted a study amongst ADp caregivers who attend support groups, found that the psychological well-being of

caregivers are likely based on a different set of factors than the well-being of those who do not attend such groups.

There was a lack of ethnic diversity among the participants, as all of the participants were white. This could be a limitation in light of Larrimore's (2003) finding that culture has an impact on caregiver attitudes and skills.

7.8 Recommendations

It is recommended that future research should include a larger sample of Alzheimer caregivers. Furthermore, culturally representative samples would promote an understanding of how Alzheimer caregiving is represented in the whole population, and provide insight into the impact of culture on the needs of AD caregivers. Furthermore, since AD caregiving can occur over many years, longitudinal studies should be conducted to get a better understanding of the long-term impact of AD on caregivers.

The potential benefits of qualitative research needs to be explored in this field. Qualitative research may yield a more in-depth understanding of the psychological factors inherent in the caregiving process.

It is hoped that the findings from this study stimulate future research in this very relevant field as caregiving increasingly becomes the norm as the number of older people and the incidence of dementia, especially of the Alzheimer's type, increase in years to come.

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NOVEMBER2007