The needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga

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Master of Social Work in Health Care
MSW (Health Care)

by

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in the

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In loving memory of …

ABSTRACT

Title: The needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga

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The worldwide ageing of the population, with an increase in associated chronic diseases, will inevitably escalate the demand for social work services at individual, group and community level. Alzheimer’s disease is one of the conditions associated with a population that is growing older. The disease was first described by Alois Alzheimer in 1906 and is characterised by progressive declines in cognitive and body functions, eventually resulting in death. It is estimated that 25 to 30 million people worldwide suffer from Alzheimer’s disease and that in 2050, 106.2 million people will be living with the disease, causing a looming global epidemic of Alzheimer’s disease (Brookmeyer, Johnson, Ziegler-Graham & Arrighi, 2007:186).

At some stage in the disease’s process, most, if not all people with Alzheimer’s, require some form of care. This care is generally provided by informal (family) caregivers in the community. Providing care to an older person with Alzheimer’s disease present multiple challenges with many factors influencing the caregiving experience. When the needs of caregivers are not met, caregiver burden may result. For the many families living in rural and impoverished areas, this additional responsibility may come as an extraordinary burden and cause unwarranted stress.

The goal of the study was to explore the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga. The guiding research question was: What are the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga?
A qualitative research approach was followed with a collective case study research design. The population for this study was caregivers providing care to persons diagnosed with Alzheimer’s disease living within the Ehlanzeni and Nkangala Rural Districts Municipalities of Mpumalanga. Non-probability purposive sampling was utilised to generate a sample.

Eleven participants who were caregivers of persons with Alzheimer’s disease living in communities within the above-mentioned municipalities were selected. Semi-structured individual interviews were conducted with participants. Interviews were voice recorded with the permission of the participants, and were transcribed by a contracted transcriber. The data gathered were analysed by the researcher and themes and sub-themes were identified. The research findings were presented by providing a profile of research participants followed by a thematic analysis of the themes and sub-themes from the transcriptions. Literature control and verbatim quotes were used to support the findings. The themes include the following: Theme One – The Alzheimer’s disease caregiver; Theme Two – Indigenous issues with regards to Alzheimer’s disease; Theme Three – Caregivers’ understanding of Alzheimer’s disease; Theme Four – The impact of Alzheimer’s disease on the caregiver and Theme Five – Support services in the community.

The conclusions of this study reflect that caregivers in black rural communities in Mpumalanga have a number of needs and challenges in providing care to a person with Alzheimer’s disease. Some of the challenges include the absence of caregiving training, stigmatisation due to indigenous beliefs, traditional healers’ diagnosis and treatment of Alzheimer’s disease, limited knowledge of caregivers about Alzheimer’s disease, adverse physical, social and psychological outcomes associated with caregiving, negative experiences with the public health care system, and the limited availability and accessibility of support services in the community.

The recommendations offered by this study can be used by professionals working in the field of gerontology to understand the needs and experiences of Alzheimer’s caregivers. Social workers can use the recommendations to find ways to make their services known to the communities, and improve their intervention and support to these caregivers.
LIST OF KEY TERMS

DEMENTIA
ALZHEIMER’S DISEASE
ALZHEIMER’S CAREGIVING
BURDEN OF CARE
PHYSICAL, PSYCHOLOGICAL AND SOCIAL IMPACT OF CAREGIVING
CAREGIVER SUPPORT AND INTERVENTIONS
ECOSYSTEMS PERSPECTIVE
GERONTOLOGY
SOCIAL WORK IN HEALTH CARE
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CHAPTER 1
INTRODUCTION

1.1 Introduction

Ross and Deverell (2010:18) underline that illness can place unendurable demands on the family because of the high levels of physical care and support, the emotional connotations of giving and receiving help, and changes in family roles and relationships. In some instances, both the individual and the family become isolated from the wider community. These demands necessitate intervention from the health care social worker to optimize the functioning and wellbeing of those affected by illness as well as their families and caregivers.

In communities where poverty and inequality in health care are prevalent, people in need of health care may come to the attention of social workers both in institutional health care settings or in community based health care settings. Doostgharin (2010:562) cites that social workers are very likely to come into contact with individuals who are experiencing unmet social needs and medical and psychological conditions, which need immediate attention. Tousijn (2012:522-523) stresses the importance of integrating health and social care policies because of the increase in the number of people affected by chronic diseases who require more holistic care. In order to conceptualise the role of the social worker in health care, it is necessary to define and understand the relationship between social work, health and wellbeing.

In July 2002, the International Federation of Social Workers agreed on a new international definition of social work, which replaced the 1982 version. The International Association of Schools of Social Work also adopted the new definition (Hare, 2004:407). The core definition, as cited in Hare (2004:409), reads as follows:

The social work profession promotes social change, problem-solving in human relationships and the empowerment and liberation of people to enhance wellbeing. Utilizing theories of human behaviour and social systems, social work intervenes at the
points where people interact with their environments. Principles of human rights and social justice are fundamental to social work.

A core concept of the new definition of social work is “wellbeing” which is increasingly used in the context of health policy. Power as cited in Strachan, Wright and Hancock (2007:278) proposes that wellbeing refers to self-reported aspects of health, which is rooted in the 1946 World Health Organisation’s (WHO) definition of health which is “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.” On the other hand, Marks, Murray, Evans and Vida Estacio, (2011:6) define health as “a state of wellbeing with physical, cultural, psychosocial, economic and spiritual aspects, not simply the absence of illness.” Wellbeing is also core to this definition. To reach this state, individuals must be enabled to accomplish aspirations, meet basic needs and adapt or cope with the environment (Dennill, 1999:13).

Both the definitions of social work and health imply that the social work profession plays a fundamental role in the social and psychological wellbeing of individuals, groups, and communities. Social work in health care was one of the first domains of professional practice to be founded and continues to be one of the largest sectors of the profession in most countries (Auslander, 2001:201). Social workers are well equipped to practise in the health care field, because of their broad perspective on the spectrum of physical, emotional and environmental factors that impact on the wellbeing of individuals and communities (Findley, 2014:19). Ryan, Merighi, Healy and Renouf (2004:412) state that “the focus of social work practice can be at the individual client level, but can also be with the family, the group, the community or wider social context.”

The worldwide ageing of the population, with an increase in associated chronic diseases, will inevitably escalate the demand for social work services at individual, group and community level. Alzheimer’s disease is one of the conditions associated with a population that is growing older. The 2009 World Alzheimer Report points out that ageing is a worldwide process that can be contributed to the successes of improved health care over the last century. People are now living longer and healthier lives resulting in a world population with a greater proportion of older
persons. The same report emphasises that an ageing population creates some challenges as well. The increase in the number of people with Alzheimer’s disease and related dementias is a significant indication of the negative effects of ageing (Alzheimer’s Disease International, 2009:2). As a result of the ageing population, dementia and particularly Alzheimer’s disease are gradually becoming a more serious public health problem (Werner, Karnieli-Miller & Eidelman, 2013:e58) and is driving governments responses in various countries (Prince, Bryce, Albanese, Wimo, Ribeiro & Ferri, 2013:64).

With a population that is growing older and public policies that compromise accessible and affordable formal care services, informal caregivers will continue to assume the immense responsibility for providing informal home care services to persons with dementia (Navaie-Waliser, Spriggs & Feldman, 2002:1249). The shift in paradigm from institutional care to community based care is supported by the objectives of the Older Persons Act 13 of 2006, which suggest that older persons must remain in their homes in the community for as long as possible.

Alzheimer’s disease does not only affect the person with the condition, as Alzheimer’s disease and caregiving are intertwined. Caregivers, family members and friends are often bewildered and confused by the behaviour of the person they know. Naleppa and Reid (2003:309) argue that caregivers may be overwhelmed and unprepared to deal with the magnitude of current and future issues that will impact on the status of the older person. Thies (2004) as quoted by Coetsee (2007:12) supports this notion and emphasises that Alzheimer’s disease impacts on people far beyond those who have it, as Alzheimer’s disease has a devastating effect on caregivers too. The same author states that at least 70 percent of those suffering from Alzheimer’s disease live at home where family members provide 75 percent of the required care. Potgieter and Heyns (2006:548) note that having a family member with dementia in the household could pose several challenges to the wellbeing of the individual involved in caregiving. The persistent nature of the psychosocial, physical and financial demands made on caregivers often results in depression, poor general health and high stress levels. The need for community-based care does not necessarily imply that communities and informal caregivers are
equipped and skilled for this immense task. It is therefore important for these communities and caregivers to be optimally capacitated to provide such services.

Providing care to the person with Alzheimer’s disease cannot be viewed in isolation. The caregiver forms part of a family system, larger community and socio-cultural environment with various interrelated factors, on several levels, influencing the caregiving experience and the coping abilities of the caregiver. The ecosystems perspective provides a theoretical framework for understanding and describing the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities and was used as theoretical framework for this study. The ecosystems perspective is discussed in more detail in chapter two.

This study’s focus revolves around the SiSwati speaking caregivers of persons living with Alzheimer’s disease in the Mpumalanga Province of South Africa. Mpumalanga means “place where the sun rises” and is bordered by Mozambique and Swaziland in the east, and Gauteng in the west. With a surface area of only 76 495 km², it is the second smallest province after Gauteng, yet has the fourth-largest economy in South Africa. The province is divided into three district municipalities, namely Ehlanzeni, Nkangala and Gert Sibande. Mpumalanga is home to just over 4 million people of which 90.7 percent are black. The principal languages are SiSwati and isiZulu. More than 68 percent of land in Mpumalanga is used for agricultural purposes (About Mpumalanga Province, 2013).

The needs and experiences of black caregivers of persons with Alzheimer’s disease living in rural communities underline the need for research from a social work perspective. During discussions with Ms Coetzee (2010/09/08), social work manager at the Mpumalanga Department of Social Development, Ms Kemp (2010/08/25), director: social services at the Suid-Afrikaanse Vrouefederasie, Ms Kirsten (2010/08/26), director of Alzheimer’s South Africa in Mpumalanga and Ms van Niekerk (2010/08/28), director of Age-in-Action in Mpumalanga, it was confirmed that black caregivers of persons with Alzheimer’s disease living in rural communities of Mpumalanga have diverse needs and experiences. Yet, it was not clear what exactly those needs and experiences are. It is, however, clear that these caregivers need specific interventions and that most social workers lack knowledge and
experience in this regard. Research on this topic will therefore fill the gap that currently exists.

1.2 Definition of key concepts

1.2.1 Needs

*New Dictionary of Social Work* (1995:41) defines *needs* as the “physical, psychological, spiritual, material and social requirements for survival, wellbeing and self-actualisation.”

*Oxford Concise Colour Medical Dictionary* (2010:489) simply defines a *need* as a “requirement or necessity.”

In this study, *needs* refer to the specific physical, psychological, spiritual, material and social requirements of the caregiver of the person with Alzheimer’s disease living in a rural community.

1.2.2 Experiences

*Experiences* can be defined as “something personally encountered, undergone, or lived through” (*The Merriam-Webster Unabridged Dictionary*, 2010).

*Reader’s Digest Word Power Dictionary* (2001:336) describes an *experience* as “practical contact with and observation of facts or events; an event or occurrence which leaves an impression on one; encounter or undergo (an event or occurrence); feel (an emotion).”

In this study, the term *experiences* will refer to daily encounters of caregivers of persons with Alzheimer’s disease living in a black rural community.

1.2.3 Care

*New Dictionary of Social Work* (1995:6) defines *care* as “the provision for people’s physical, psychological and material needs where they are unable to provide these for themselves.”
The term *care* is described by *Reader’s Digest Word Power Dictionary* (2001:135) as “the provision of what is necessary for the welfare and protection of someone or something; look after and provide for the needs of.”

In this study, *care* will refer to the provision for the needs, at physical, psychological and material level, of the person with Alzheimer’s disease, by a caregiver in a black rural community.

**1.2.4 Caregiver**


Cayton, *Graham and Warner.* (2002:191) describe a *caregiver* as “a person who provides help and support to another person, usually a relative or friend. More specifically, a caregiver is someone who looks after another person who needs help with daily living and who would not otherwise be able to live independently.”

In this study, *caregiver* will refer to the person providing care and support to the person with Alzheimer’s disease living in a black rural community.

**1.2.5 Alzheimer’s disease**

*Oxford Concise Colour Medical Dictionary* (2010:24) describes Alzheimer’s disease as the most common form of dementia, occurring in middle age or later. “It is characterized by memory impairment and, as the disease progresses, language difficulties, apraxia, and visuospatial problems.”

Cavanaugh and Blanchard-Fields (2006:132) describe Alzheimer’s disease as “an irreversible form of dementia characterized by progressive declines in cognitive and body functions, eventually resulting in death.”

*Alzheimer’s disease* can thus be defined as a degenerative and debilitating brain disease associated with cognitive failure, in which the person loses abilities such as memory, recognition, reasoning, body functions, and the ability to perform the daily activities of living.
1.2.6 Rural area

Health Systems Trust (1998) suggests that non-urban or rural areas include commercial farms, small settlements, rural villages and other areas, which are further away from towns and cities. The definition includes semi-urban areas, which are not part of a legally proclaimed urban area, but adjoin it.

The Rural Development Framework defines rural as “the sparsely populated areas in which people farm or depend on natural resources, including the villages and small towns scattered across these areas. In addition, rural areas include the large settlements in the former homelands, created by the apartheid removals, which depend on migratory labour and remittances for their survival” (Department of Land Affairs, 1997).

For the purposes of this study, rural areas will refer to those areas situated around farms and villages in Mpumalanga and which do not form part of towns or cities and have limited infrastructure and resources.

1.3 Literature review

Dementia is a generic term that describes the cognitive decline in brain function. There are many causes of dementia, such as Alzheimer’s disease, head injury and AIDS. These types of dementia are irreversible (Mc Donnell & Ryan, 2011:238; Tanna, 2004:4). Dementia affects one in 88 of the general population. Age is the leading risk factor and the prevalence doubles every five years from about 5 to 8 percent at age 65 to 70 to 15 to 20 percent at age 75 to 80 and up to 40 to 50 percent over the age of 85 (Barry & Yuill, 2010:220; Richards & Sweet, 2009:1168).

Truter (2010:10) describes dementia as a chronic, global, usually irreversible deterioration of cognition. Dementia is defined by the same author as “an acquired deterioration in cognitive abilities that impairs the successful performance of activities of daily living.” Memory is the most common ability lost with dementia. In addition to memory, other mental abilities are also affected in dementia, for example language, spatial orientation, calculation, decision making, judgment, problem solving, and abstract reasoning (Truter, 2010:10). This decline is often described in
literature as a “loss of self” (Piiparinen & Whitlatch, 2011:186). It is therefore evident that dementia is a debilitating disease affecting the mental and social functioning and wellbeing of the individual suffering from the disease.

Alzheimer’s disease is described as the most common cause of dementia (Alzheimer’s Disease International, 2013:1; Cayton et al., 2002:1; Truter, 2010:10). Kelly (2000:11) indicates that 50 – 70 percent of all diagnosed cases of dementia can be attributed to Alzheimer’s disease whereas the Alzheimer’s Association (2011a:8) estimates that Alzheimer’s disease accounts for 60 to 80 percent of dementia cases.

Burns and Iliffe (2009:467) define Alzheimer’s disease as “a chronic progressive neurodegenerative disorder”, characterized by three primary groups of symptoms. The first group is *cognitive dysfunction*, which includes memory loss, loss of higher level planning and intellectual coordination skills, and language difficulties. The second group comprises *psychiatric symptoms and behavioural disturbances* such as delusions, agitation, depression, and hallucinations. The third group includes *difficulties with performing basic activities of daily living* such as eating, dressing, shopping, etc.

Alzheimer’s Disease International (2009:8) estimates that there were 35.6 million people with dementia in 2010, the numbers nearly doubling every 20 years to an expected 65.7 million in 2030 and 115.4 million in 2050. Dementia can therefore be described as a growing phenomenon in an ageing population. Koutsavlis and Wolfson (2000:93) support this notion by stating that “old age is all too commonly a time of impaired neurological function.” Due to demographic changes, research suggests that the major increase in the prevalence of dementia will occur in developing countries such as South Africa (Cohen, 2000:32; Wimo, Winblad & Jönsson, 2010:98).

The incidence of dementia in South Africa has not been determined conclusively and there is a general belief that Alzheimer’s disease mainly affects white people (De Beer, 2009; Kalula, Ferreira, Thomas, De Villiers, Joska & Geffen, 2010:449; Van der Poel & Pretorius, 2009:452). Kalula et al. (2010:229) argue that this can be
ascribed to various factors, including non-presentation of cases of mental illness owing to stigma; differential survival rates; signs and symptoms of dementia being accepted by sufferers' families and caregivers as normal in ageing; access barriers to health care; and preferential use of complementary medicine or traditional healing. De Beer (2009) endorses this argument by citing that dementia is severely under-diagnosed in South Africa and that the symptoms of dementia are often ascribed to common causes of witchcraft. This prevents persons with dementia and their caregivers from getting the necessary medical attention and social support. The researcher is of the opinion that this is especially the case in black rural communities in South Africa, hence the focus of this study on the unique needs and experiences of caregivers of persons with Alzheimer's disease living in these communities.

As Alzheimer's disease progresses, the person becomes more dependent and this has an impact on those providing care (Mc Donnell & Ryan, 2011:239). Many research studies have been conducted with regards to Alzheimer’s disease and the caregiver. Research in the field of psychology focuses on the psychological health implications of caregiving (Coetsee, 2007:1-103) and the neuropsychological symptoms and premorbid temperamental traits in Alzheimer’s dementia (Cassimjee, 2008:95-115). Medical research is mainly concerned with the risk factors associated with and the treatment of Alzheimer’s disease (Helzner, Luchsinger, Scarmeas, Cosentino, Brickman, Glymour & Stern, 2009:343-348), whereas epidemiological studies endeavour to determine the incidence and prevalence of Alzheimer’s disease (Prince et al., 2013:63-75; Van der Poel & Pretorius, 2009:451-454). However, there is a dearth in literature with regards to the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities, and more specifically from a South African and social work perspective. This study aims to address this gap in research. Alzheimer's disease and caregiving are discussed in detail in chapter two.

1.4 Rationale, problem statement and research question

The population of older persons throughout the world is increasing at a rapid rate. It is projected that the number of older persons would have reached the two billion mark by 2050. The most rapid increase is taking place in the developing world, with
Africa alone projected to have between 204 and 210 million older persons by the year 2050. The growing number of older persons is an international concern and governments, the private sector, non-governmental organisations, and society in general must be prepared to deal with this demographic trend, taking into consideration the special needs of this population group (HelpAge International, 2003:5; Parton, 2007:18; WHO, 2002a:6).

Louw and Louw (2009:11) rightfully state that the systematic ageing of the population will no doubt be one of the most distinctive demographic trends of the 21st century. In this regard, Hamilton-West (2011:130) says that this demographic trend is associated with functional decline and an increased risk of morbidity. It is therefore imperative that the health care system, informal caregivers, and social workers in South Africa should be prepared and skilled to deal with the growing number of older persons and the challenges associated with ageing as cognitive deterioration in the older population is recognized as a major cause of disability that significantly impacts on older persons, their families, and society in general.

With the anticipated global increase in the number of dementia cases, the 2010 World Alzheimer Report cautions that the societal cost of dementia is already enormous and is significantly affecting every health and social care system in the world. The estimated worldwide costs of dementia were US$604 billion in 2010 (Alzheimer’s Disease International, 2010:4).

The Global Burden of Disease Report as quoted by Alzheimer’s Disease International (2009:9) estimates that dementia accounts for 4.1 percent of the total disease burden among people 60 years and older. For the reasons stated before, dementia is described by De Witt and Ploeg (2014:2) and the WHO (2012:v) as a “public health priority” and by Holtzman et al. (2011:1) as “a global health problem of immense proportions.” The stigma and social exclusion associated with dementia, presents a significant public health challenge (WHO, 2012:vi) and prompted the global health community to recognize the need for action and to prioritize dementia on the public health agenda.
At some stage in the disease’s process, most, if not all people with dementia, require some form of care. Alzheimer’s Disease International (2009:9) and the WHO (2012:68) confirm that, in all parts of the world, this care is generally provided by informal (family) caregivers in the community. Most caregivers are spouses and the vast majority of them are women.

The unavailability of institutional care in rural areas of South Africa has been confirmed by a national audit of residential facilities, which was commissioned by the National Department of Social Development during 2010. The audit report highlights that the distribution of such facilities is disproportionate in the wealthier provinces of Gauteng and the Western Cape, with a distinct lack of facilities in poorer provinces. Owing to out-migration and urbanization amongst younger persons, older persons are disproportionately represented in the most rural and poorest provinces of the country. At the same time, the audit found that the majority of residential facilities (79%) are concentrated in metropolitan formal areas or small urban formal areas. Only five percent are in informal or squatter areas, while 16 percent are in rural areas (Department of Social Development, 2010). Goins, Spencer and Byrd (2009:140) mention that living in a rural setting has been consistently linked with limited availability and access to formal health services, yet little is known about the effect of living in rural communities on the provision of informal care. It can therefore be assumed that informal caregivers in the community care for the majority of older persons in rural areas, including those with dementia.

Dementia and Alzheimer’s disease are overwhelming, not only for the people who have it, but also for their families and caregivers. Providing care to a person with the disease can result in substantial strain for those who provide most of the care (WHO, 2012:2-3). Coetsee (2007:12) emphasises that caregivers of persons with Alzheimer’s disease experience high levels of emotional and physical stress and are twice as likely as non-caregivers to report mental health complications.

Furnish as quoted by Coetsee (2007:12) points out that the specific difficulties of caring for someone with Alzheimer’s disease is distinct from any other form of frailty; and that this challenge is not fully appreciated. High levels of loneliness and depression among these caregivers are reported (Beeson, 2003:136-137; Coetsee,
Ekwall and Hallberg (2007:833) explain that, besides stress and emotional strain, caregiving is also known to have an adverse effect on the physical health of caregivers. Potgieter and Heyns (2006:548) report that feelings of guilt, anger, sadness, loss, anxiety and entrapment were found to be common amongst these caregivers. In addition, Butler (2008:1260) reports that the life expectancy of caregivers is reduced as a result of high levels of stress and anxiety. However, research findings suggest that caregiving outcomes differ among caregivers from different racial groups (Napoles, Chadiha, Eversley & Moreno-John, 2010:389; Sun, Kosberg, Leeper, Kaufman & Burgio, 2010:291). The stressors associated with dementia caregiving are often compounded by a lack of awareness and understanding of the condition, and the stigma and blame consequently attached to the caregiver (WHO, 2012:72). Maintaining the health and wellbeing of caregivers, and providing them with the necessary support, will become more significant as disparities in the availability of formal support services become more acute and prevalent.

Caregivers moreover face additional barriers when seeking services for themselves. In many countries, support services are not readily available, and should they be available, there are barriers to access and uptake, such as lack of recognition of the caregiving role and poor understanding of dementia. Cultural approaches to caregiving can result in refusal of outside help due to fears of “losing face” (WHO, 2012:79). Hinton, Fox and Levkoff as quoted by Ivey, Laditka, Price, Tseng, Beard, Liu, Fettermen, Wu and Logsdon (2012:807) state that “the caregiving experience may be shaped by culturally-based views about the role of caregivers and recipients, notions of distress of burden, ideas about what constitutes ‘good’ and ‘bad’ care, family styles of interaction and beliefs about ‘normal’ and ‘abnormal’ aging.” It can therefore be said that providing care to the person with dementia does not only affect all aspects of a person’s life, but is also influenced by a number of factors.

Even though there are a number of detrimental psychological and health outcomes associated with dementia caregiving, the research paradigm has in recent years shifted its focus toward the positive aspects of dementia caregiving. Lee and Choi (2012:424) and Roberto and Jarrott (2008:103) mention various studies where caregivers reported positive outcomes such as having the opportunity to give back,
an appreciation from family members, development of coping skills in the caregiver role, a sense of self-worth and mastery, marital satisfaction, greater family cohesion and finding personal strengths. It is therefore important to not only focus on the negative outcomes associated with dementia caregiving, but to build on the positive experiences of caregivers.

In most countries, a poor knowledge and understanding of dementia prevails. Dementia is often viewed to be an ordinary part of ageing or a condition for which there is no treatment. This has an impact on people with dementia, their families and caregivers, and their support structure in various ways. Low awareness levels are conducive to stigmatization and isolation. Poor understanding further produce barriers to early diagnosis and to accessing continuing medical and social care, resulting in a significant gap and delay in treatment (Hodgson & Cutler, 2004:388; WHO, 2012:8). The social worker involved in community health care therefore has a considerable responsibility to educate individuals, families, and communities about the ageing process and dementia care.

The complexity of working with persons living with dementia and their families requires competent and effective practice and an exceptional level of professional skill and ability. The need for social workers to obtain specialised knowledge and skills in dementia care will continue to develop as new directions in medical technology, pharmaceutical interventions and behavioural treatments combine to extend life expectancy and, in so doing, increase the prevalence of dementia (Marhall & Tibbs as quoted by Kaplan & Berkman, 2011:364). Noyes, Hill, Hicken, Luptak, Rupper, Dailey and Bair (2010:9) rightfully state that, in order to develop effective interventions, service providers in the field of gerontology must have a comprehensive understanding of dementia and the caregiving experience.

The needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in South Africa have not been researched in their entirety from a social work perspective. As a result, the needs and experiences of these caregivers remain unclear. This study aims to contribute to the understanding and knowledge base of the needs and experiences of such caregivers in order to render effective social work and other intervention services.
In this study, the researcher wants to explore what the unique needs and experiences are of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga.

Based on the above, the research question guiding this study is formulated as follows:

*What are the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga?*

**1.5 Goal and objectives of the study**

The goal of the research can be described as the study’s aim, purpose, researcher’s intention or “dream” and relates to the research question. Ivankova, Creswell and Clark (2007:278) explain that the research purpose is the overall intent of the study, whereas Fouché and Delport (2011:108) note that the goal of the research study indicates the central thrust of the study.

The goal of this study is:

To explore the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga.

To achieve the goal of the research study, the following objectives are pursued:

- To conceptualise Alzheimer’s disease as a condition, including incidence, clinical features, etiology, risk factors, diagnosis, treatment and aspects of caregiving from the ecosystems perspective;
- To identify the current support systems available in black rural communities to caregivers of persons with Alzheimer’s disease;
- To identify the indigenous beliefs about Alzheimer’s disease in black rural communities in Mpumalanga;
- To explore the challenges faced by caregivers of persons with Alzheimer’s disease in black rural communities; and
• To make recommendations for professional support services to caregivers of persons with Alzheimer’s disease in black rural communities.

1.6 Research methodology

A qualitative research approach was followed to explore and describe the needs and experiences of caregivers of persons with Alzheimer's disease living in black rural communities in Mpumalanga. Applied research was chosen, using the case study research design, specifically the collective case study design, as it would assist the researcher to further his understanding about the social issues relating to the caregiver of a person with Alzheimer’s disease.

The population in this study was caregivers of persons with Alzheimer's disease living in the Ehlanzeni and Nkangala black rural communities of Mpumalanga. Non-probability, purposive sampling was applied in the recruitment of research participants. Eight participants were selected from the Ehlanzeni district and three from the Nkangala district of Mpumalanga, according to specific criteria.

Face-to-face, semi-structured interviews were used in the study as a data-collection method to generate detailed, qualitative data regarding the needs and experiences of caregivers. The interviews related to aspects of providing care to persons with Alzheimer’s disease in black rural communities, while still allowing considerable flexibility in scope and depth. The interview schedule consisted of various themes that focused on different aspects of Alzheimer’s disease and caregiving. The interviews were recorded and transcribed, whereafter the data were analysed. Themes and sub-themes were generated from the data, which are discussed in depth in chapter three of this research report, together with the research methodology.
1.7 Ethical issues

Ethical issues were regarded as important throughout the research process to protect participants from any possible harm or loss. Informed consent was obtained by means of signed informed consent forms, which outlined the research purpose and process and prepared the participants for the research interviews. Participants were informed that participation in the research was voluntary and that they had the right to withdraw from the research process at any time. Confidentiality and privacy were maintained by keeping the names and other identifying particulars of participants private, and by assigning numbers to participants during the research study. All participants were debriefed during the research process to protect them from any possible harm. The researcher was honest, truthful and transparent throughout the study to avoid the deception of participants. These ethical considerations are discussed in more detail in chapter three.

1.8 Limitations of the study

Due to the limited scope of the study, the small size of the sample \((N = 11)\) and the fact that only a small portion of the caregiving population could be accessed, the results cannot be generalised. However, the results should provide an indication of what could be expected from a similar sample.

The researcher had to employ the services of a translator as the interviews were conducted in rural areas where the spoken language is predominantly SiSwati. The researcher experienced difficulties to communicate abstract concepts such as “isolation”, “depression” and “burden.” The researcher is of the opinion that, should he have been able to conduct the interviews in siSwati, richer descriptive qualitative data would have been generated.

Very little research has been done about caregiving of Alzheimer’s patients in rural communities in South Africa, which made it difficult for the researcher to correlate and substantiate the research findings with scientific literature. The researcher, in most instances, had to rely on international studies to control the findings.
1.9 Contents of research report

Chapter 1 provides the reader with the general introduction and orientation to the study, including the problem formulation, the goals and objectives of the study, research question, research design, the type of research, sampling, data collection and analysis, ethical considerations, limitations of the study, and definition of key concepts.

Chapter 2 provides an in-depth literature review of dementia as medical condition, and more specifically Alzheimer's disease. The incidence, stages, clinical profile, etiology, and caregiving in the context of Alzheimer's disease are discussed.

Chapter 3 explains the methodology of the study, and includes the research design, aims of the study and research question, sampling procedures, ethical considerations, data collection and analysis. The research findings are discussed according to themes and sub-themes. Narratives from the research interviews and research are used to substantiate the findings.

Chapter 4 provides a summary with the purpose of indicating how the goals and objectives of the study were achieved. Conclusions are drawn and recommendations made for the benefit of social work in the field of dementia care.

The following chapter will focus on dementia, Alzheimer's disease and caregiving.
CHAPTER 2
ALZHEIMER’S DISEASE

2.1 Introduction

Chapter two conceptualises the phenomenon of dementia and more specifically Alzheimer’s disease as the most common cause of dementia and the leading cause of cognitive and functional deterioration in old age. This includes definitions of medical terms and key concepts to facilitate understanding of terminology used throughout this chapter.

Dementia, as an umbrella term for a group of mental conditions characterised by memory impairment and the degeneration of the brain, is broadly discussed in terms of its etiology, sub-categories and incidence. Specific attention is given to Alzheimer’s disease and the discussion includes the incidence and the clinical features of this disease. The etiology of Alzheimer’s disease is discussed in terms of hypotheses suggested in literature and the risk factors associated with the development of the disease. Various staging models for Alzheimer’s disease have been developed that indicate the progression of the disease. The two most commonly used models are discussed. A multi-disciplinary approach is suggested for the diagnosis of Alzheimer’s disease. The use of neuropsychological assessment and the use of more recently developed biomarkers are highlighted. The section on Alzheimer’s disease is concluded by a discussion on the pharmacological and non-pharmacological management of the disease.

At some stage of the disease progression, affected persons will become care dependent. Caregiving in the context of Alzheimer’s disease is conceptualised in terms of the caregiving tasks associated with the stages in the development of the disease followed by the demographic profile of an Alzheimer’s caregiver. As the caregiver functions within a larger system, the physical, psychological and social impact of caregiving on the caregiver, the demographic, social and cultural factors influencing the caregiving experience and interventions to improve the health and wellbeing of caregivers are discussed with the ecosystems perspective as theoretic
departure point. Chapter two is concluded with the pivotal role of the social worker working in the field of dementia care.

2.2 Definition of key concepts

2.2.1 Ecosystems perspective
“The underlying philosophical position of the ecosystems perspective is that the person is connected to others, as well as to the social institutions, cultural forces, and the physical space that make up his or her environment” (Wakefield, 1996:7).

2.2.2 Dementia
“Dementia is an overall term for diseases and conditions characterized by a decline in memory or other thinking skills that affects a person’s ability to perform everyday activities” (Alzheimer’s Association, 2014:5).

2.2.3 Alzheimer’s disease

2.2.4 Caregiver
“A person who provides help and support to another person, usually a relative or friend. More specifically, a caregiver is someone who looks after another person who needs help with daily living and who would not otherwise be able to live independently” (Cayton et al., 2002:191).

2.2.5 Caregiving
“...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting” (Shulz as quoted by Alzheimer’s Disease International, 2009:54).
2.2.6 Gerontology
“Gerontology is the study of aging across disciplines” (Siegler, Hooker, Bosworth, Elias & Spiro, 2010:156).

2.3 Medical terms

2.3.1 Acquired Immune Deficiency Syndrome (AIDS)
“A disease, caused by a virus transmitted in body fluids, in which there is a severe loss of cellular immunity that leaves the sufferer susceptible to infection and malignancy” (Oxford Concise English Dictionary, 2009:27).

2.3.2 Agnosia
“Impaired ability to recognise objects or people” (Austin, Bezuidenhout, Du Plessis, Jordaan, Lake, Nel, Pillay, Ure, Visser, von Kroisiqk, Vorster & Burke, 2009:526).

2.3.3 Aphasia
“…an acquired communication disorder caused by brain damage, characterized by an impairment of language modalities: speaking, listening, reading and writing…” (Chapey & Hallowell as quoted by Darley, 2010:65).

2.3.4 Apraxia
“Apraxia is the inability to carry out learned and purposeful activities. It is a cognitive impairment that influences activities of daily living directly” (Donkervoort, Dekker & Deelman, 2002:299-300).

2.3.5 Computerised Tomography (CT)
“A form of X-ray examination in which the X-ray source and detector rotate around the object to be scanned and the information obtained can be used to produce cross-sectional images by computer” (Oxford Concise Colour Medical Dictionary, 2010:161).

2.3.6 Diabetes Mellitus
“A condition that occurs when the body cannot use glucose (a type of sugar) normally, resulting in high levels of blood sugar” (Austin et al., 2009:531).
2.3.7 Deoxyribonucleic acid (DNA)
“The genetic material of nearly all living organisms, which controls heredity and is located in the cell nucleus” (Oxford Concise Colour Medical Dictionary, 2010:218).

2.3.8 Electroencephalography (ECG)
“The technique for recording the electrical activity from different parts of the brain and converting it into a tracing called an electroencephalogram (EEG)” (Oxford Concise Colour Medical Dictionary, 2010:236).

2.3.9 Human Immunodeficiency Virus

2.3.10 Hypercholesterolemia
“Hypercholesterolemia is the presence of raised or abnormal levels of cholesterol in the blood. Cholesterol is a fatty substance manufactured by the body (mainly the liver). Higher total cholesterol levels lead to increased risk of cardiovascular disease” (Choudhary, Al-Hadithy & Simon, 2009:721).

2.3.11 Hypertension
“Abnormal high blood pressure - the force of blood pushing against the walls of arteries as it flows through them” (Austin et al., 2009:534). “Hypertension is defined as mean systolic blood pressure of at least 140 mm Hg, mean diastolic blood pressure of at least 90 mm Hg, or both” (Egan, Zhao & Axon, 2010:2044).

2.3.12 Lumber Puncture
“A procedure performed under local anaesthetic in which cerebrospinal fluid is withdrawn by means of a hollow needle inserted into the subarachnoid space in the region of the lower back. The fluid obtained is examined for diagnosis of disorders of the brain” (Oxford Concise Colour Medical Dictionary, 2010:427).

2.3.13 Magnetic Resonance Imaging (MRI)
“A diagnostic imaging technique based on the emission of electromagnetic waves from the body when the patient is placed in a strong magnetic field and exposed to radiofrequency radiation” (Oxford Concise Colour Medical Dictionary, 2010:435).
2.3.14 Obesity

“The prevalence of obesity is commonly assessed using body mass index (BMI), a height/weight formula with a strong correlation to body fat content. WHO criteria define obesity as a BMI of at least 30 kg/m²” (WHO, 2002b:60).

2.3.15 Positron Emission Tomography (PET)

“The individual is injected with a tracer substance attached to radioactive isotopes. The substance then interacts with glucose, blood, or oxygen. When any part of the brain becomes active, the glucose, blood or oxygen flow to these areas of the brain and detectors can then identify the location of the isotopes. In this way, we can see which parts of the brain are working, and which parts are not working” (Austin, 2009:52).

2.3.16 Single-photon Emission Computed Tomography (SPECT)

“It is similar to a PET scan, but a different tracer substance is used” (Austin, 2009:52).

2.4 Theoretical foundation – ecosystems perspective

Since the early 1980’s researchers have generally agreed that humans do not develop without the influence of their personal ecosystem and the larger ecosystem, of which they are part (Sturges & Hardesty, 2005:155). Yet, research studies on rural caregiving have been criticised in literature for not including an explicit description of a theoretical model or conceptual framework (Goins, Spencer & Byrd, 2009:60). Although there are no theories specific to rural caregiving, the ecosystems perspective of Meyer (1983) could be applied to caregiving in rural settings, and in the view of Findley (2014:89), this perspective can help to empower the individual within the health care system.

Historically, social work method has maintained its concern with the individuals and their environment; however, it has not always viewed both as equally significant (Greene, 2011:11). More recently, the ecosystems perspective has become the most widely used approach for understanding the relationship between individuals and their social environment. It views the individual and larger social systems as separate but related elements that transact with each other in relationships, and
which have a mutual influence on each other (Kondrat, 2002:435). The human ecosystem is thus made up of the totality of an individual’s interaction with his or her environment and contains the elements of wholeness and the interdependency of parts (Morgan & Brosi, 2007:422). The ecosystems perspective is fundamentally a combination of thoughts that originate from the ecological perspective and general systems theory (Wakefield, 1996:3). Although both perspectives focus on systems, Van Wormer and Besthorn (2010:19) explain that each offers a different way to think about how systems impact one another and how people adapt to their changing circumstances and surroundings. System theorists, for example, focus on the roles that individuals play to help maintain order within their systems. Ecological theorists take a broader view by looking at the settings in which people play out those roles and the impact of those settings on people’s functioning. The broader ecosystems perspective, according to Gitterman (2001:xv), reflects the complex relations between people and their environments.

As the ecosystems approach takes into account the multiple and complex transactions that take place between individuals within their families and environments, this approach is described in recent literature as relevant to social work practice. Social work is concerned with how people cope with changing environments or with changes in their own abilities to deal with their surroundings. The ecosystems approach is further described as a form of practice based on understanding the needs, challenges and strengths of individuals and their families; and the resources and barriers in the environment (Northen & Kurland, 2013:18-19). As social workers often deal with vulnerable populations, such as older persons and their caregivers, and often intervene at the interface between the individual and society, the ecosystems perspective can make social workers knowledgeable about ways to overcome the social, psychological and cultural obstacles facing vulnerable populations (Park, Castellanos-Brown & Belcher, 2010:661; Van Wormer & Besthorn, 2010:4).

The ecosystems perspective corresponds with the person-in-environment perspective, but it broadens the approach by taking into account levels of systems as the macro (i.e. the cultural context of the individual), meso (i.e. interactions between families and formal systems), and micro (i.e. the setting where the individual lives)
levels of interventions. This perspective accentuates the interrelatedness or interdependence of human problems/issues, life situations, and the social conditions in the individual’s life where the situation can be assessed for both strengths and weakness in these interactions. Most significantly, the ecosystems perspective creates boundaries that allow the social worker to see the individual in his or her own sociocultural environment, which provides a tremendous amount of flexibility to accommodate individual needs and create client-specific treatment interventions (Findley, 2014:88-89).

Modelling human health from an ecosystems perspective makes use of systems theory that recognises human health as influenced and conditioned by factors at various levels and scales including those related to the individual, family, community, surrounding biophysical and socio-economic environments, and national and global policies (Dakubo, 2010:31). It therefore takes into account the biological, psychological and social functioning of individuals, as well as the environmental forces that impact on the functioning of individuals.

From an ecosystems approach, the purpose of social work is an improvement in the relationship between people and their physical and social environments (Mattaini, 2008:35). That purpose, according to Northen and Kurland (2013:17-18), encompasses the achievement of positive changes in the psychosocial functioning of individuals, families and groups and in the conditions in the environment to lessen obstacles and provide opportunities for more satisfying and productive social living.

Although the ecosystems perspective stands out as the most influential and widely accepted generic view in social work, the perspective has been widely criticised. Wakefield (1996:6) argues that the ecosystems perspective offers no help whatsoever in deciding what intervention to use, and offers no predictable judgements. Wakefield further states that it is not a model with prescriptions for addressing cases, it does not specify outcomes and therefore it can lay no claim to being a practice theory. It is literally just a perspective, that is, a useful way of looking at social work cases, and not a substantive theory or model that makes specific empirical claims. However, Wakefield does mention that the ecosystems
perspective is clinically useful as it offers a comprehensive method of assessment and corrects practitioner biases toward person-centred intervention.

Caregiving and Alzheimer’s disease cannot be separated from each other. For this reason, the ecosystems perspective provides a theoretical perspective for understanding and describing the needs and experiences of caregivers of persons with Alzheimer’s disease. It is further used to illustrate how the various levels, ranging from the microsystem to the larger macrosystem, play a role in the in the experience of the Alzheimer’s caregiver and to facilitate an understanding of the interrelationships between caregivers and their environments.

2.5 Dementia

For some older persons, cognitive wellbeing and performance remains constant over the course of their lifetime, with only a slow and minor decline in short-term recollection and response times. For others, however, this common age-related deterioration in cognitive function progresses into a severe condition of cognitive impairment, or into different forms of dementia, such as Alzheimer’s disease. This loss of cognitive function – the ability to reason, think, learn and remember, radically interferes with everyday functioning (Mungas, 2010:1) and is a primary concern of ageing adults (Mogle & Sliwinski, 2013:49).

Older people with dementia exist in nearly every country of the world. Alzheimer’s Disease International (2009:43) accentuates that, with worldwide increases in population size and life expectancy, dementia and Alzheimer’s disease have become a world health problem. The global number of people affected by Alzheimer’s disease was 26.6 million in 2006, and it was estimated that $156 billion is spent annually to care for persons with dementia worldwide (Rocca, Petersen, Knopman, Hebert, Evans, Hall, Gao, Unverzagt, Langa, Larson & White, 2011:80).

Dementia is not a specific disease but, according to Cavanaugh and Blanchard-Fields (2006:132) and Zarit and Zarit (2012:43), refers to a syndrome or a family of diseases. These diseases are characterised by cognitive and behavioural deficits involving some form of permanent harm to the brain. Alzheimer’s Disease
International (2010:8) refers to dementia as a condition that can be caused by a number of progressive disorders that influence behaviour, memory, thinking and the ability to carry out daily activities. More than a hundred types of dementia have been identified of which Alzheimer’s disease, vascular dementia and Lewy body dementia are the most common (Cayton, Graham & Warner, 2002:2). Dementia is thus an umbrella term for a group of mental conditions that are characterised by the degeneration of the brain (Louw & Louw, 2009:278) and where the essential feature is the occurrence of numerous cognitive deficits (American Psychiatric Association, 2000:148). Cavanaugh and Blanchard-Fields (2006:132) profoundly state that “in dementia one can literally lose one’s mind, being reduced from a complex, thinking, feeling human being to a confused, vegetative victim unable even to recognise one’s spouse and children.” This statement depicts the progressive and debilitating nature of dementia and the impact on the physical and psychosocial functioning of the individual.

2.5.1 Etiology of dementia

Rathmann and Conner (2007:1499) indicate that there are numerous possible causes of dementia. The dementias are, according to Pillay (2009:75-79), sub-categorised according to presumed etiology. Kaplan and Sadock as quoted by Pillay (2009:75-79) identify the following most prevalent sub-categories of dementia:

2.5.2 Dementia of the Alzheimer’s type

Dementia of the Alzheimer’s type is the most common cause of dementia, occurring in fifty percent or more of all cases. The incidence of the disease increases drastically with age (Mangialasche, Solomon, Winblad, Mecocci & Kivipelto, 2010:702; Reis, 2005:91; Truter, 2010:10). Alzheimer’s disease can affect different people in different ways; however, the most common symptom begins with gradually worsening difficulty in remembering new information. This is because disruption of brain cell function usually begins in regions involved in forming new memories (Alzheimer’s Association, 2011a:209). As damage spreads, individuals experience more complex difficulties, affecting their everyday functioning. Later symptoms include impaired judgement, trouble speaking, swallowing and walking, disorientation and behaviour changes (Alzheimer’s Association, 2009:5). Alzheimer’s disease is discussed in more detail in section 2.6.
2.5.3 Vascular dementia
Vascular dementia is the second most common type of dementia and causes cognitive impairment in elderly people (Roman, Erkinjuntti, Wallin, Pantoni & Chui, 2002:426; WHO, 2012:19). It constitutes about 5 percent to 10 percent of dementias (Rogan & Lippa, 2002:16). Vascular dementia was previously known as multi-infarct or post-stroke dementia (Alzheimer’s Association, 2013:210) and occurs after stroke in 25 percent of patients (Black, 2011:49). Vascular dementia describes a group of vessel disorders, which is caused by different types of vascular lesions that finally contribute to the development of dementia (Thal, Grinberg & Attems, 2012:816). This type of dementia is initially characterised by impaired judgement or ability to make plans as opposed to memory loss associated with the initial symptoms of Alzheimer’s disease (Alzheimer’s Association, 2013:210).

2.5.4 Dementia due to other medical conditions
In this category, the dementia is the result of diseases or trauma to the head. Kaplan and Sadock, as quoted by Pillay (2009:76), point out the following as some of the common diseases resulting in dementia:

2.5.4.1 Parkinson’s disease
Parkinson’s disease is a disorder that affects nerve cells in the part of the brain controlling muscle movement and is commonly associated with depression. It is a disease of the basal ganglia and belongs to a group of disorders called motor system disorders, which are the result of the loss of dopamine-producing brain cells. The sufferer typically demonstrates slow movement (Pillay, 2009:76). As Parkinson’s disease progresses, it often results in a severe dementia similar to Alzheimer’s disease (Alzheimer’s Association, 2013:210) and is associated with cognitive impairment (Rajput, Rajput & Rajput, 2005:33). The onset of Parkinson’s disease is commonly between the ages of 50 and 79 (Louw & Louw, 2009:280).

2.5.4.2 Huntington’s disease
Huntington’s disease is a progressive and fatal disorder (Ross & Tabrizi, 2011:83) which results from genetically influenced degeneration of brain cells in subcortical areas of the brain and is passed genetically from parent to child (Pillay, 2009:76). The disease usually begins between ages 35 and 50 and is characterised by the gradual onset of involuntary flicking movements of the arms and legs; the inability to
sustain a motor act such as sticking out one’s tongue; prominent psychiatric disturbances such as hallucinations, paranoia, and depression; and eminent personality changes, such as swings from apathy to manic behaviour. Cognitive impairment typically appears late in the disease (Cavanaugh & Blanchard-Fields, 2006:144).

2.5.4.3 Pick’s disease
Pick’s disease is characterised by atrophy or shrinking of the frontal and temporal regions of the brain. Also referred to as fronto-temporal dementia, it is most common in men who have first-degree relatives with the disorder. Dementia associated with Pick’s disease is hard to distinguish from Alzheimer’s disease, although there is some executive dysfunction present in the early stages of the disease. Personality and behavioural changes are prominent with cognitive functions remaining intact (Pillay, 2009:77). Language impairment is found in majority of cases of Pick’s disease and the age of onset varies from 40 to 65 years (Thibodeau & Miller, 2013:420).

2.5.4.4 Dementia with Lewy bodies
Dementia with Lewy bodies is associated with abnormal deposits of the protein alpha-synuclein that forms inside nerve cells in the brain (Alzheimer’s Association, 2011a:210) and accounts for 10 to 15 percent of dementia cases (Walker, McKeith, Rodda, Qassem, Tatsch, Booij, Darcourt & O’Brien, 2012:1). People with the disease experience symptoms which are common in Alzheimer’s disease, but are more likely to have initial or early symptoms such as visual hallucinations, sleep disturbances and muscle rigidity or other movement features associated with Parkinson’s disease (Alzheimer’s Association, 2013:210).

2.5.4.5 Creutzfeldt-Jacob disease
Creutzfeldt-Jacob disease is caused by the misfolding of prion protein throughout the brain. It is a rapidly progressing and fatal disorder characterised by impaired memory and coordination and causes behaviour changes (Alzheimer’s Association, 2011a: 210). The incidence of the disease is estimated at 1 per 1000 000 cases of the general population per year. The average age of onset is 65 years and the average disease duration is four months (Gambetti, Puoti, Calli & Zou, 2010:263-265).
2.5.4.6 Human Immunodeficiency Virus (HIV) disease
Infection of the central nervous system due to HIV results in dementia that is known as Acquired Immune Deficiency Syndrome (AIDS) dementia complex or HIV dementia. This type of dementia is marked by forgetfulness, slowness, poor concentration, and difficulties with problem solving. Behavioural manifestations most commonly include apathy and social withdrawal. These symptoms may be accompanied by delirium, delusions, or hallucinations (Pillay, 2009:78). Mental performance and motor functioning continue to deteriorate as HIV dementia progresses, and incontinence usually occurs. In the terminal phase, patients are bedridden, stare vacantly, and have minimal social and cognitive interaction (Cavanaugh & Blanchard-Fields, 2006:144). HIV dementia remains prevalent in South Africa where HIV infection figures are high, but access to antiretroviral treatment is often limited (Joska, Westgarth-Taylor, Hoare, Thomas, Paul, Myer & Stein, 2011:95). As explained by Robbins, Remien, Mellins, Joska and Stein (2011:587), HIV dementia is the most severe form of HIV-associated neurocognitive disorders and is one of the most common causes of dementia among adults 40 years and younger.

2.5.4.7 Dementia related to head trauma
Depending on the severity of head injury, survivors may suffer from a wide variety of symptoms such as neurological disorders, cognitive, emotional and behavioural impairments, including dementia related to head trauma (Dams-O’Connor, Spielman, Hammond, Sayed, Culver & Diaz-Arrastia, 2013:199; Lee, Hou, Lee, Hsu, Huang & Su, 2013:e62422). Head injury-related dementia is characterised by emotional lability, speech impairment and impulsivity (Pillay, 2009:78). The same author reports that the prevalence of head trauma is extremely high in South Africa given the high rate of motor vehicle accidents and high level of violence.

2.5.4.8 Substance-induced persisting dementia
Substance-induced persisting dementia results from the abuse of drugs or medication, or from toxin exposure (Pillay, 2009:78). One of the consequences of long-term chronic alcoholism is Wernicke-Korsakoff syndrome. This disease is associated with a chronic deficiency of thiamine and causes major memory impairment and loss of other cognitive functioning. The condition is treatable if the
vitamin deficiency is detected early in the process, and cessation of excessive alcohol consumption usually is associated with improved cognitive functioning as well (Cavanaugh & Blanchard-Fields, 2006:144).

Dementia is a term used to represent various disorders of the brain that usually result in progressive and severe loss of memory and cognition and can therefore be described as a family of different diseases, where each sub-category is associated with specific characteristics, age of onset, etiology, progression and duration.

2.5.5 Incidence of dementia
Population ageing leads to more people being affected by disorders whose prevalence increases with age and are having a profound impact on the emergence of the global dementia epidemic (WHO, 2012:12). By 2050, the number of people above the age of 60 years will have increased by 1.25 billion, accounting for 22 percent of the world’s population (Prince, et al., 2013:64), with four-fifths living in Africa, Asia or Latin America (WHO, 2012:12). The 2011 census report of South Africa indicates an increase from 9.6 to 10.6 percent in the population of older persons since 1996. The total number of persons 65 years and older living in South Africa is 4.3 million out of a total population of 51.8 million (Statistics South Africa, 2012:18). Figure 2.1 below shows the increase in the population older persons in South Africa between 1996 and 2011.

Dementia may occur at any age, but affects primarily the elderly. Truter (2010:10) mentions that dementia affects 5 – 20 percent of persons over the age of 65 years and that its incidence increases significantly with age. Estimates as high as 25-50 percent for persons over the age of 85 years are reported by Bourgeois, Seaman and Servis (2004:86). The incidence of the different types of dementia depends on the age of the person, the person’s country of origin, access to medical care, as well as racial or ethnic background (Truter, 2010:10). Although the Alzheimer’s Association (2009:11) reported in 2009 that women are more likely than men to develop dementia, as they generally live longer than men, the 2011 report refers to studies conducted where no gender specific differences could be found in the incidence of new dementia cases (Alzheimer’s Association, 2011a:215). In the United States of America, African American’s and Hispanics are more likely than whites to develop dementia, but these differences may be explained by other factors than race (Alzheimer’s Association, 2009:11) such as health conditions, lower levels of education, and other differences in socio-economic characteristics (Alzheimer’s Association, 2011a:216).

Alzheimer’s Disease International (2010:4) estimates that there are 35.6 million people living with dementia worldwide and that this number will increase to 56.7 million by 2030 and 115.4 million by 2050. Each year, 4.6 million new cases are predicted (WHO, 2012:12) with rapid increases forecasted for China, India and Latin America (Prince, et al., 2013:63). Ames, Chiu, O’Connor and Lautenschlager (2010:234) emphasise that most new cases of dementia will emerge in developing countries. A projected 68 percent of the world’s elderly will live in these countries by 2025 (Ineichen, 2000:1673).

Very few epidemiological studies on dementia have been carried out in Africa (Kalula & Petros, 2011:31; Mkize, 1998:770; WHO, 2012:12), despite the fact that the life expectancy in Africa countries is projected to increase rapidly (Ineichen, 2000:1673). A series of studies from Nigeria have produced consistently low rates for dementia. Studies that are more recent have indicated rather higher rates, but still lower than surveys conducted elsewhere. There are several possible reasons for these findings, including differential survival rates, reluctance to seek medical assistance, the hiding of cases by relatives because of stigma, poor access to medical care, the
feeling that the older persons have come to the end of their useful lives, and unreliable case-finding systems (Pillay, 2009:75). In addition, Kalula and Petros (2011:31) argue that the diagnosis and management of dementia is not a priority for less developed countries’ health care systems as these systems face multiple and competing demands for health care, mainly for diseases such as HIV and AIDS, tuberculosis, malaria as well as reproductive and child health. These diseases are more demanding health care priorities for less developed countries.

Pilot research conducted by the University of the Free State indicates that the incidence of dementia in South Africa is higher than initially estimated and has disputed the assumption that dementia is less prevalent among urban black communities. Preliminary findings show that approximately 6 percent of persons aged 65 years and older have developed dementia. Previous estimates for Southern Africa have been set at around 2.1 percent (University of the Free State, 2010). Whilst clinical tests are underway, Alzheimer’s South Africa (2014) estimates that 730 000 people in South Africa suffer from dementia.

2.6 Alzheimer’s disease

Alois Alzheimer (1864 – 1915) first described the disease that would be named after him at a meeting of the South West German Psychiatrists in 1906. He presented a case of a 51-year old woman who developed progressive dementia, accompanied by focal signs, delusions and hallucinations. She died at the age of 55. On post-mortem, her brain was found to contain numerous senile plaques and newly observed structural changes (see Figure 2.2). These abnormal brain tissues are now known to be the characteristic features of Alzheimer’s disease. (Ballenger, 2006:6; Cassimjee, 2008:95).
In the century since the discovery of Alzheimer’s disease, scientists have made significant progress in understanding how the disease affects the brain and how it affects persons suffering from the disease. Yet, the precise changes in the brain that causes Alzheimer’s disease, and the order in which they occur, largely remain unknown (Alzheimer’s Association, 2011a:209; Alzheimer’s Association, 2013:209).

Alzheimer’s disease is described in literature as the most common cause of dementia (Alzheimer's Association, 2011a:8; Truter, 2010:10) and the percentage of dementias attributable to Alzheimer’s disease ranges from 60 percent to over 90 percent, depending on the setting and diagnostic criteria (American Psychiatric Association, 2013). The disease is characterised by a gradually progressing loss of cognitive functioning and an increasing disorientation regarding time and place (Naleppa & Reid, 2003:13) where the cognitive deficits are not due to other central nervous system disorders that cause gradual deficits in memory or cognition, systemic conditions that are known to cause dementia, or the persisting effects of a substance (American Psychiatric Association, 2000:154). Cavanaugh and Blanchard-Fields (2006:132) refer to Alzheimer's disease as a form of “fatal dementia” and the mean survival rate after diagnosis is approximately 10 years. However, some individuals can live with the disease for as long as 20 years (American Psychiatric Association, 2013).
2.6.1 Incidence of Alzheimer's disease


The disability weight of Alzheimer's disease on persons older than 60 years of age is considered larger than that of cardiovascular disease, cancer, musculoskeletal disorders and stroke (Minati, Edington, Bruzzone & Giaccone, 2009:95). The same authors estimate that 25 to 30 million people worldwide suffer from Alzheimer's disease and that this number will triplicate by 2040. In 2050, it is projected that one in 85 persons or 106.2 million people worldwide will be living with the disease (Brookmeyer et al., 2007:186; Holtzman et al., 2011:1), causing a looming global epidemic of Alzheimer's disease.

Alzheimer's Association (2013:215) provides updated statistical information on the incidence of Alzheimer's disease in the United States of America. The information is based on the outcome of the 2010 United States (US) Census and the Chicago Health and Ageing Project, a population-based study of chronic health disorders of older people. It is estimated that 5.2 million Americans of all ages had Alzheimer's disease in 2013. This includes an estimated 5.0 million people 65 years and older and 200 000 individuals younger than 65 years of age with younger onset of Alzheimer's disease. The study provides the following breakdown concerning the incidence of Alzheimer's disease in the United States of America:

- One in nine people age 65 and older (11%) has Alzheimer's disease;
- About one-third of people age 85 and older (32%) have Alzheimer's disease; and
- Of those with Alzheimer's disease, an estimated 4% are younger than 65, 13% are 75 to 84 years old, and 38% are 85 years or older.

The US-based findings correlate with global age estimates quoted by other authors (American Psychiatric Association, 2013; Chin & Weiner, 2007:7; Ringman,
2005:228) and confirm the understanding that advanced age remains the most significant risk factor for developing Alzheimer’s disease.

As already discussed previously, epidemiological studies have not conclusively determined the incidence of dementia and Alzheimer’s disease in South Africa. However, with the expected worldwide increase in the population of older persons, especially in developing countries, it can be anticipated that the incidence of Alzheimer’s disease in South Africa will increase accordingly. When considering the worldwide increase in the incidence of Alzheimer’s disease, together with a population that is ageing, it is apparent that the disease could hold serious implications for a large part of the older population.

2.6.2 Clinical features of Alzheimer’s disease

Alzheimer’s disease affects people in different ways and individuals progress from mild to severe Alzheimer’s disease at different rates. Greeff (2009:364) asserts that the essential feature of Alzheimer’s disease is the presence of dementia of insidious onset and a gradually progressive course for which all other particular causes have been ruled out by history, physical examination and other specific investigations. However, Rathmann and Conner (2007:1499) indicate that some cases progress more rapidly. The dementia involves a multifaceted loss of intellectual abilities, such as memory, abstract thinking, judgement and other higher cortical functions, as well as changes in behaviour and personality (Greeff, 2009:364). As quoted by Contreras, Vargas, Ramos and Velandia (2007:411), Alzheimer’s disease is clinically characterised by progressive memory loss, intellectual impairment, and affective and psychotic disorders. Although early-onset of Alzheimer’s disease and late-onset of Alzheimer’s disease may differ (Mendez, Lee, Joshi & Shapira, 2012:413), the most common clinical features of the disease include the following:

2.6.2.1 Memory impairment

The most common symptom of Alzheimer’s disease is the gradually worsening ability to remember new information (Alzheimer’s Association, 2013:209) and presents in the earliest stages of the disease (Minati et al., 2009:100; Rogan & Lippa, 2002:12). This memory impairment is in excess of age-related cognitive decline; in other words, memory must be sufficiently poor to interfere with daily functioning. Articles
are mislaid, faces are not recognised, and disorientation regarding time or place occurs. Statements need to be repeated and the individual is forgetful. Initially, there is difficulty in learning new information (short-term memory impairment), but later, long-term memory is also affected. Increasingly, the individual lives in the past (Potocnik, Page & Hugo, 2001:337) and in the advanced stages of the disease, persons may actually forget their birthday, occupation, schooling, family members, and sometimes even their name (Pillay, 2009:74). This decline in memory does not only affect the persons suffering from Alzheimer’s disease, but also their close friends and families.

2.6.2.2 Behavioural and personality changes

Behavioural changes occur in about 90 percent of persons with Alzheimer’s disease that negatively impact on cognitive and functional status, increase caregiver burden and contribute to the possibility of institutionalisation. Such changes include apathy, social isolation and withdrawal, agitation, irritability, anxiety, aggression, increased confusion, wandering, peculiar motor behaviour and vocalisation, and sleep disturbances (Minati et al., 2009:101; Yiannopoulou & Papageorgiou, 2013:21). Research conducted by Cassimjee, Stuart and Marchetti-Mercer (2005:237) also reported symptoms of fatigue and tiredness.

Personality changes involve either an accentuation or, less commonly, an alteration of pre-morbid traits. Aggressive, paranoid, impulsive or histrionic tendencies may become exaggerated. There is a loss of initiative, and the individual becomes increasingly withdrawn and apathetic. The individual may also become self-centred, hypochondriacal, irritable and careless, and is sometimes described as having entered his or her “second childhood”. Impaired impulse control may be present, in the form of social disinhibition, exhibitionism, inappropriate spending of money and clumsy shoplifting. Affection, sensitivity and interest may disappear with decreasing rapport. The mood is not usually depressed and an emotional shallowness is more common (Potocnik et al., 2001:337). However, a study conducted by Tractenberg, Weiner, Patterson, Teri and Thal (2003:94) found that the prevalence of depressive symptoms in Alzheimer’s disease was high at 78.4 percent, followed by agitation (77.6%). Cassimjee (2008:97) refers to various studies where hallucinations, delusions, psychosis and hypomania were prevalent among persons with
Alzheimer’s disease and where 50 percent of persons with the disease eventually manifested with psychotic disturbances, which increased as the disease progressed. In the study conducted by Tractenberg et al. (2003:94), 69.3 percent of the persons with Alzheimer’s disease exhibited psychotic symptoms. It is evident that the behavioural and personality changes associated with Alzheimer’s disease increase the need for care and supervision as it affects the ability of the person to function independently.

2.6.2.3 Intellectual impairment

Thinking becomes more primitive and the person cannot cope with novel tasks as higher cortical functions are affected. Potocnik et al. (2001:337-338) and Rathmann & Conner (2007:1500) explain that the following may become evident:

- **Dysphasia**
  The individual becomes unable to read, watch television or listen to the radio. Language may become vague, imprecise, stereotyped and dysphasic. The person may find it difficult to understand social communication. Speech becomes progressively impaired, is characterised by sentences broken into numerous phrases, and pauses in search of a forgotten word. Very often, an unrelated phrase or word is substituted for a forgotten one, or sentences are incomplete. As the disease progresses, sentences cannot be completed at all resulting in obvious dysphasia.

- **Agnosia**
  Agnosia manifests itself in the inability to perform acquired motor functions. Individuals can no longer dress themselves, or may have difficulty in closing and opening doors, or folding a letter and placing it in an envelope.

- **Impairment in executive function**
  Impairment in executive function may be one of the initial symptoms of Alzheimer’s disease. The individual struggles with complex tasks such as managing their financial affairs, using a television set and taking part in previously valued hobbies and games. Lack of insight and impaired judgement in social, financial, and other practical matters are often observed.
2.6.2.4 Physical changes
As Alzheimer's disease progresses, the individual appears unduly weak and frail, looks older than his or her chronological age, and is stooped in posture with a slow, shuffling gait. Sphincter control is impaired. There is poor appetite during the day, with bouts of confusion and restlessness at night (Potocnik et al., 2001:338).

There may also be an increase in frequency of the grasping and sucking reflex, gegenhalten reflex (resistance to passive limb movement), corneo-mandibular reflex (clamping of the jaw when the cornea is touched), lip puckering, snout reflex (lip pursing when touched) and palmomental reflex (unilateral mouth and chin retraction when the palm is stroked). The person becomes increasingly disoriented and confused and hallucinations may manifest. In the final stages of the disease, the person loses all ability to communicate, move or think, and reverts to an infantile state of behaviour (Rathmann & Conner, 2007:1500).

The disturbances in Alzheimer's disease have, according to Cassimjee (2008:97), both significant clinical and social implications. On a clinical level, psychotic disturbances can reduce the quality of life of the individual and compound cognitive impairment. On a social level, the occurrence of hallucinations and delusions may increase caregiver burden and impact significantly on the quality of life of both caregiver and the person with Alzheimer’s disease. It is therefore imperative to recognise and not only treat cognition, but also behavioural disruption (Moretti, Torre, Antonello, Cazzato & Bava, 2002:338) as this could improve the quality of life of persons with Alzheimer’s disease and alleviate the burden on caregivers.

2.6.3 Etiology of Alzheimer's disease
The cause of Alzheimer’s disease continues to be unknown, although extensive research is being conducted to unravel the mystery (Alzheimer’s Association, 2013:209; Cayton et al., 2002:22; Greeff, 2009:364; Thompson-Heisterman, 2006:738;). What is known is that Alzheimer’s disease is associated with a degenerative process in the brain resulting in the death of neurons and subsequent loss of neurotransmitters (Marseille & Silverman, 2006:123) and an abnormal change in the sequence of chemical pairs inside genes (Alzheimer’s Association, 2013:212).
Multiple and diverse studies are investigating the role of various bio-psychosocial factors, including genetics, vascular changes, inflammation, oxidative stress, metabolic factors, beta-amyloid and tau proteins, hormones, and growth factors as well as lifestyle and educational levels. The etiology of Alzheimer’s disease may be multifactorial, a combination of genetic vulnerability and exposure to environmental and psychosocial stressors (Thompson-Heisterman, 2006:738). Several hypotheses have been supported by varying amounts and quality of data. These hypotheses include:

2.6.3.1 Acetylcholine alterations
Nerve cells need neurotransmitters for processing and communicating different information in the brain. Acetylcholine is such a neurotransmitter and is associated with cognition, processing memory, learning and motor function. Low levels of acetylcholine are associated with memory loss and impaired learning ability (Ali, 2012:28-29). Research has indicated that in persons with Alzheimer’s disease, the enzyme that is required to produce acetylcholine is significantly reduced. This decrease of acetylcholine reduces the amount of the neurotransmitter that is released to cells in the cortex and hippocampus, resulting in a disruption of the cognitive processes (Townsend, 2005:209).

2.6.3.2 Accumulation of aluminium
Exposure to different toxic substances can result in the development of various neurological disorders (Ali, 2012:26). Several studies have reported higher concentrations of aluminium in the brains of persons with Alzheimer’s disease than in those of healthy older persons without dementia. Conversely, high concentrations of aluminium have also been found in persons with other types of dementia. Therefore, aluminium as a causative factor is probably not specific to Alzheimer’s disease. The current consensus is that aluminium compounds accumulate only in a brain that is already damaged (Rathmann & Conner, 2007:1501; Townsend, 2005:2009). More research is necessary to determine the role of aluminium in the etiology of Alzheimer’s disease.
2.6.3.3 Alterations in the immune system

Immunological abnormalities have been reported in persons with Alzheimer’s disease (Rathmann & Connor, 2007:1501). Although several studies have indicated that antibodies are produced in the Alzheimer’s brain, it is not known what stimulates the production of the antibodies. The reactions are usually auto-antibody production – a reaction against the self – suggesting a possible alteration in the body’s immune system as an etiological factor in Alzheimer’s disease (Townsend, 2005:2009). Some cases of familial Alzheimer’s disease may be secondary to a transmissible agent, such as a slow virus, and genetic factors may control the response to the virus and thus determine which family members will be affected (Rathmann & Conner, 2007:1501). Although there is no concluding evidence demonstrating the infectious origin of Alzheimer’s disease, research is continuing in this area.

2.6.3.4 Head trauma

Head injury is considered as a major risk for developing Alzheimer’s disease. Individuals with severe traumatic brain injury are 4.5 times at risk of developing the disease compared to those with no head injury (Alzheimer’s Association, 2013:214). Motor vehicle accidents are a major cause of traumatic brain injury in South Africa (Pillay, 2009:75). Table 2.1 outlines the prevalence of traumatic head injury in Southern Africa. The high prevalence of traumatic head injury in Southern Africa can be considered as major risk factor for developing Alzheimer’s disease. Section 2.6.4.8 provides a more detailed discussion on the correlation between traumatic head injury and Alzheimer’s disease.

Table 2.1: Traumatic brain injury in Southern Africa (Pillay, 2009:79)

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>PREVALENCE</th>
<th>POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angola</td>
<td>21 957</td>
<td>10 978 552</td>
</tr>
<tr>
<td>Botswana</td>
<td>3278</td>
<td>1 639 231</td>
</tr>
<tr>
<td>South Africa</td>
<td>88 896</td>
<td>44 448 470</td>
</tr>
<tr>
<td>Swaziland</td>
<td>2338</td>
<td>1 169 241</td>
</tr>
<tr>
<td>Zambia</td>
<td>22 051</td>
<td>11 025 690</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>7343</td>
<td>12 671 860</td>
</tr>
</tbody>
</table>
2.6.3.5 Genetic factors

There is clearly a familial pattern with some forms of Alzheimer's disease. Some families exhibit a pattern of inheritance that suggests possible autosomal-dominant gene transmission. Some studies indicate that early-onset cases are more likely to be familial than late-onset cases and that from one-third to one-half of all cases may be of the genetic form. Close relatives of Alzheimer's patients have a 4.3 times greater risk of developing the disease than the general population (Rathmann & Connor, 2007:1501). Some researchers believe that there is a correlation between Alzheimer's disease and the alteration of a gene found on chromosome 21. People with Down’s syndrome who have a supplementary copy of chromosome 21 have been found to be unusually susceptible to Alzheimer’s disease (Townsend, 2005:2009).

Various hypotheses have been suggested to understand the etiology of Alzheimer's disease. Continued research to identify the precise cause, or combination of causes, of Alzheimer's disease will possibly result in more effective treatment options.

2.6.4 Risk factors associated with Alzheimer's disease

A number of familial, lifestyle-related, and environmental factors have been identified that increase the risk of individuals to develop Alzheimer's disease. The risk factors associated with Alzheimer's disease are as follows:

2.6.4.1 Age

Progressing age remains to be the most significant risk factor for Alzheimer’s disease (Ali, 2012:23; Alzheimer’s Association, 2012:135), although Alzheimer's disease is not a typical part of ageing (Alzheimer’s Association, 2013:213; Cassimjee et al., 2005:226). Alzheimer's disease is described by Wolf-Klein, Pekmezaris, Chin and Weiner (2007:77) as “a common illness of the elderly population” and typically occurs in persons over 65 years of age with the incidence and prevalence increasing significantly thereafter (Ringman, 2005:228). However, persons younger than the age of 65 years can also develop the disease (Alzheimer’s Association, 2013:213). Seven percent of individuals diagnosed with Alzheimer's disease are between 65 and 74 years, 53 percent are between 75 and 84 years, and 40 percent are 85 years
and older (American Psychiatric Association, 2013). It is clear that advancing age increases the risk of developing Alzheimer’s disease.

2.6.4.2 Gender
Alzheimer’s disease, according to some studies, occurs more frequently in females than in males. Females tend to live longer than males and thus have a higher chance of developing Alzheimer’s disease (Ali, 2012:24). Vina and Lloret (2010:S527) argue that a possible explanation for the higher incidence of Alzheimer’s disease in women is that they suffer higher rates of obesity, diabetes, and other conditions which increase the likelihood of developing the disease. Aderinwale et al. (2010:418) and Ali (2012:24) suggest that the higher incidence of Alzheimer’s disease in females can be attributed to the loss of estrogen after menopause as this hormone protects the brain against memory loss and decline in mental functioning. Yet, Gilbeard (2000:108) and Kivipelto, Helkala, Nissinen, Soininen and Tuomilehto (2002:86) argue that the role of gender is still controversial and that incidence studies have reported inconsistent results on the occurrence of Alzheimer’s disease by gender. In this regard, Carter et al. (2012:1019) state, “Because women survive to later ages than men, it is impossible to know if men who died would ever have developed Alzheimer’s disease at the same rate as women.” It is evident that further research is required to determine the role of gender as a risk factor for developing Alzheimer’s disease, taking into consideration the differential life expectancy rates among males and females.

2.6.4.3 Family history
Individuals who have a family member with Alzheimer’s disease, such as a parent, brother or sister, are at greater risk of developing the disease than those who do not have a first-degree relative with the disease. Those who have more than one first-degree relatives suffering from Alzheimer’s disease are at even higher risk of developing the disease (Alzheimer’s Association, 2013:213). Ali (2012:24) mentions that if one parent suffers from the early-onset type of Alzheimer’s disease (onset between the ages of 30 and 40 years), the chances are that 50 percent of the children will develop the disease, whilst having a parent or sibling with Alzheimer’s disease significantly increases the risk of developing the late-onset type of the disease. Five to ten percent of all cases of Alzheimer’s disease show autosomal
dominant inheritance (Swearer, O'Donnell, Parker, Kane & Drachman, 2001:157) and it is generally accepted that there is a strong genetic component to Alzheimer’s disease (Aderinwale et al., 2010:416). Hereditary is thus regarded as a risk factor for developing Alzheimer’s disease, and more specifically, where a first-degree relative suffered from the disease.

2.6.4.4 DNA mutations

Living organisms contain DNA that serves as a blueprint and a carrier of genetic information that determines an individual’s characteristic and regulates the functioning of cells in organisms. In some instances, DNA can undergo permanent changes resulting in errors in genetic codes that can cause diseases and disorders to occur. These changes are known to be DNA mutations. They are irreversible, and lead to the development of genetic disorders. Alzheimer’s disease is associated with genetic mutations in one of three genes: amyloid precursor protein, presenin-1 and presenin-2. Alterations in any of the genes result in an increased production of beta-amyloid protein that clumps together and form highly toxic plaques in the brain, leading to neural degradation and death. The presence of beta-amyloid protein can be seen in all persons with Alzheimer’s disease and is one of the conclusive biomarkers used for the diagnosis of the disease (Ali, 2012:25). It is generally accepted that amyloid plaques and neurofilbrillary tangles underlie the dementia associated with Alzheimer’s disease (Aderinwale et al., 2010:414).

In addition to the presence of the amyloid precursor protein, presenlin-1 and presenlin-2 genes, Alzheimer’s Association (2013:213) explains that individuals with the ε4 form of the gene apolipoprotein E (APOE ε4) are at increased risk of developing Alzheimer’s disease. APOE ε4 is one of the most common forms of the APOE gene, which provides a blueprint for a protein that transmits cholesterol in the bloodstream. Each individual inherits one form of the APOE gene from each parent. Those who inherit one APOE ε4 gene, as opposed to the ε2 or ε3 forms of the gene, have an increased risk of developing Alzheimer’s disease. However, inheriting the APOE gene does not guarantee that an individual will develop Alzheimer’s disease, suggesting that other genetic factors must contribute to risk for the disease (Holtzman et al., 2011:10). DNA mutations and the inheritance of certain genes can therefore increase the risk of individuals to develop Alzheimer’s disease.
2.6.4.5 Mild cognitive impairment

Mild cognitive impairment refers to mild, but measurable changes in thinking abilities in a person that are noticeable to the person affected, family members and friends, but do not affect the individual’s ability to perform daily activities. Individuals with mild cognitive impairment are at greater risk of developing Alzheimer’s disease than those without any form of cognitive impairment (Alzheimer’s Association, 2013:213). Petersen and O’Brien (2006:148) describe mild cognitive impairment as the transitional stage between the cognitive changes of ageing and the earliest clinical features of dementia, which suggests that mild cognitive impairment is actually an early stage of Alzheimer’s disease. However, not all persons with mild cognitive impairment will develop Alzheimer’s disease (Alzheimer’s Association, 2013:213).

2.6.4.6 Cardiovascular disease risk factors

Certain lifestyle habits that result in high blood pressure, high cholesterol levels, atherosclerosis and diabetes are considered risk factors for developing Alzheimer’s disease. These conditions can contribute to the damage and death of brain cells by hardening the blood vessels and blocking oxygen flow to the brain (Ali, 2012:25; Alzheimer’s Association, 2013:213). The following modifiable lifestyle factors associated with cardiovascular disease increase the risk of Alzheimer’s disease:

- **Hypertension**
  
  Hypertension is an established risk factor for Alzheimer’s disease and can aggravate the progression of the disease (Qiao, Lu, Wang, Guo & Qu, 2014:3). Aderinwale et al. (2010:417) refer to the Cardiovascular Health Study All Stars that demonstrated that cardiovascular disease and hypertension are related to cognitive impairment in older persons and emphasise that the management of cardiovascular disease and hypertension can enhance cognitive functioning in older persons. Kivipelto, Helkala, Nissinen, Soininen and Tuomilehto (2002:85) explain that research has indicated that individuals with high systolic blood pressure (≥160 mm Hg) levels in midlife have a significantly higher risk of developing Alzheimer’s disease later in life than those with normal systolic blood pressure levels due to vascular damage caused by hypertension.
• **Diabetes mellitus**
A positive relationship between diabetes and Alzheimer’s disease has been established (Aderinwale et al., 2010:417; Alzheimer’s Association, 2013:213; Kivipelto et al., 2002:91). Type 2 diabetes mellitus is the most common form of diabetes and is caused by insulin resistance in peripheral tissues and is associated with ageing, obesity, a family history of diabetes, physical inactivity, and often Alzheimer’s disease (De la Monte & Wands, 2008:1102). Decreased catalytic activity of insulin-degrading enzyme responsible for the degradation of amyloid peptides is evident in persons with Alzheimer’s disease (Levy, 2007:591).

• **Cholesterol**
Hypercholesterolemia is indicated in literature as a risk factor for Alzheimer’s disease (Ali, 2012:25; Qiao et al., 2014:3). Kivipelto et al. (2002:85) note that individuals with high serum cholesterol levels (≥ 6.5 mmol/l) at midlife had a significant higher risk of Alzheimer’s disease later in life than those with normal serum cholesterol levels. Elevated cholesterol is believed to disrupt cholesterol balance in neuronal cell membranes and increases the risk of Aβ plaque formation associated with Alzheimer’s disease (Aderinwale et al., 2010:417).

• **Obesity**
Obesity often stems from childhood lifestyle behaviour and is indicated by a body mass index of [BMI]>30 (De la Monte & Wands, 2008:1103; WHO, 2002b:60). Certain cardiovascular disorders are attributed to the secondary complications of obesity, including hypertension, atherosclerosis, Type 2 diabetes, and ageing. The effect of obesity on the cardiovascular system is now evident. Increased vascular disease may affect memory function. Obesity results in insulin resistance. Insulin plays a major role in maintaining normal cognitive function. Hence, abnormalities in the insulin-signalling pathway may contribute to impairment of memory function similar to those seen in persons with Alzheimer’s disease (Naderali, Ratcliffe & Dale, 2009:445).

• **Educational level**
Ali (2012:26) refers to various studies that demonstrated that individuals with low education levels (less than six years) are more likely to suffer from Alzheimer’s
disease, while individuals who achieved higher formal education have stronger cognitive reserves that provide greater resilience against brain damage and therefore a lesser risk to develop Alzheimer’s disease. The cognitive reserve hypothesis suggests that having more years of education, increases the connections between neurons in the brain and enables the brain to compensate for the early brain changes of Alzheimer’s disease by using alternate routes of neuron-to-neuron communication to complete a cognitive task (Alzheimer’s Association, 2013:214).

Literature furthermore suggests that persons with higher occupational attainment have a lower risk of developing Alzheimer’s disease than people with lower occupational attainment. Although the mechanism underlying this pattern is unknown, research proposes that the effects of education and occupation are due to their association with frequency of participation in cognitively stimulating activities (Wilson & Bennett, 2003:87). However, some scientists believe that the increased risk of Alzheimer’s disease among those with lower educational and occupational attainment may be attributed to other factors common to people in lower socio-economic groups such as increased risk for disease in general and less access to medical care (Alzheimer’s Association, 2013:214).

2.6.4.8 Traumatic brain injury
Traumatic brain injury is the leading cause of death and severe disability in people under 45 years of age and is predominantly caused by motor vehicle accidents (Finnie & Blumbergs, 2002:679). Moderate and severe traumatic brain injury is associated with an increased risk of developing Alzheimer’s disease. Traumatic brain injury is the disruption of normal brain function caused by a blow or jolt to the head or penetration of the skull by a foreign object. Moderate traumatic brain injury is defined as “a head injury resulting in loss of consciousness or posttraumatic amnesia that lasts more than 30 minutes.” If loss of consciousness or posttraumatic amnesia lasts more than 24 hours, the injury is considered severe. Individuals who suffered moderate traumatic brain injury are twice at risk of developing Alzheimer’s disease compared with no head injury while severe traumatic brain injury is associated with 4.5 times the risk of developing the disease (Alzheimer’s Association, 2013:214).
It is evident that a number of modifiable and non-modifiable factors are associated with a higher risk of developing Alzheimer’s disease. Cardiovascular risk factors are often associated with lifestyle diseases such as obesity, diabetes mellitus, hypercholesterolemia and hypertension that can be improved by healthy lifestyles.

### 2.6.5 Stages in the development of Alzheimer’s disease

Olde Rikkert, Tona, Janssen, Burns, Lobo, Robert, Sartorius, Stoppe and Waldemar (2011:357) report that several common patterns of symptom development are present in individuals with Alzheimer’s disease and that various methods of staging derived from these patterns have been developed. Such staging systems provide valuable frames of reference for understanding disease progression, developing appropriate treatment strategies and for future planning. However, it is important to remember that all stages are artificial indicators in a process that can differ significantly from one person to another (Alzheimer’s Association, 2007:1).

The course of Alzheimer’s disease is inclined to be gradually progressive. A common pattern is a subtle onset, with early loss of recent memory followed by the development of apraxia, agnosia and aphasia after several years. Many individuals show personality changes, increased irritability, and other behavioural signs and symptoms, starting in the early stages and becoming most prominent in the middle stages of the disease. In the later stages, individuals may develop gait and motor disturbances and eventually become mute and bedridden. The typical duration of the illness from onset of symptoms to death is eight to ten years (American Psychiatric Association, 2000:156), and depends on the time of diagnosis and the age of the individual leading to a longer survival rate in individuals diagnosed at a younger age (Greeff, 2009:364).

Although a number of staging models have been developed (Olde Rikkert et al., 2011:359), the two most commonly used are the three- and seven-stage models (Ali, 2012:118).

### 2.6.5.1 The three-stage model of Alzheimer’s disease

The three-stage model of Alzheimer’s disease comprises a mild or preclinical stage, a moderate or mild cognitive impairment stage, and a severe or dementia due to
Alzheimer’s disease stage. The three-stage model, as described by Ali (2012:96-104) and Thompson-Heisterman (2006:741), is summarised in Table 2.2.

Table 2.2: The three-stage model of Alzheimer’s disease (Ali, 2012:96-204; Thompson-Heisterman, 2006:104)

<table>
<thead>
<tr>
<th>STAGE</th>
<th>DURATION</th>
<th>SYMPTOMATOLOGY</th>
</tr>
</thead>
</table>
| STAGE 1 Mild or preclinical  | 2-4 years         | • Frequently repeating oneself  
• Regularly misplacing articles  
• Inability to recall familiar words to use in conversation  
• Withdrawal from formerly enjoyed activities  
• Awareness of and frustration with one’s own “forgetfulness”  |
| STAGE 2 Moderate or mild cognitive impairment | 2-10 years | • Decreased ability to perform daily activities  
• Difficulty finding way around one’s own neighbourhood and home  
• Disruptive behaviours (wandering, pacing)  
• Hallucinations and delusions  
• Inability to perform complex motor activities  
• Problems with visual perception (and thus susceptibility to accidents)  
• Frequently needs supervision  
• Temperament fluctuations, from composed and tranquil to screaming and argumentative  
• Deterioration apparent to friends and family  |
| STAGE 3 Severe or dementia due to Alzheimer’s disease | 1-3 plus years | • Lost capacity of self-care  
• Lost use of language  
• Only has minimal long-term memory  
• Must have 24-hour, seven-days-a-week care |

The three-stage model provides a clear understanding of the progressive nature of Alzheimer’s disease from early onset to the severe or final stage, and how the disease affects the individual at each stage during its course. The model further illustrates that Alzheimer’s disease is initially characterised by mild impairment of cognitive abilities, which eventually results in the incapacity of individuals to function independently. The expected duration of each stage is indicated in years.
2.6.5.2 The seven-stage model of Alzheimer's disease

Barry Reisberg developed the seven-stage model of Alzheimer's disease, also called the Global Deterioration Scale or Functional Assessment Staging (FAST) scale. It was the first model to describe the vital symptoms and the clinical course of Alzheimer's disease as it causes damage to the brain in detail (Ali, 2012:118). The seven stages of the model, and the associated symptoms as described by (Ali, 2012:119-124) and Alzheimer's Association (2007:1-3), are summarised in Table 2.3.


<table>
<thead>
<tr>
<th>STAGE</th>
<th>SYMPTOMATOLOGY</th>
</tr>
</thead>
<tbody>
<tr>
<td>STAGE 1 No cognitive impairment</td>
<td>No memory impairments are experienced by unaffected individuals or apparent to a health care practitioner during a medical interview.</td>
</tr>
<tr>
<td>STAGE 2 Very mild decline</td>
<td>Individuals experience memory lapses, forget common words or names or where they have placed items such as keys, spectacles, etc. However, these difficulties are not apparent during a medical examination or obvious to family, friends or co-workers.</td>
</tr>
</tbody>
</table>
| STAGE 3 Mild cognitive decline | Early-stage Alzheimer’s disease can be recognised in some, but not all, individuals with these symptoms. Certain deficiencies are noticed by family members, friends and co-workers. Problems with memory or concentration may be detected in clinical testing or during a comprehensive medical interview. Such common difficulties include:  
  - Problems finding familiar words or names, evident to family and close friends  
  - Difficulty to remember names when introduced to new people  
  - Deterioration in work and social settings apparent to others  
  - Difficulties reading a passage and remembering material  
  - Losing or misplacing items  
  - Decreased ability to organise or plan |
| STAGE 4 Moderate cognitive decline | At this stage, an in-depth medical interview identifies limitations in the following areas:  
  - Decreased awareness of recent events  
  - Decreased ability to carry out perplexing mental arithmetic e.g. counting backwards from 100 in 7s  
  - Decreased ability to execute intricate daily tasks such as managing finances  
  - Impaired memory of own personal history  
  - The individual may appear unresponsive and withdrawn, particularly in mentally and socially challenging situations |
<table>
<thead>
<tr>
<th>STAGE</th>
<th>SYMPTOMATOLOGY</th>
</tr>
</thead>
</table>
| **STAGE 5 Moderate severe cognitive decline** | Significant deficits in memory and cognitive function develop during this stage. Some assistance with activities of daily living becomes necessary. At this stage, individuals may:  
• Have difficulties to recall important details such as their telephone number, address or name of the school which they attended  
• Become disoriented with regards to the date, day of the week, season or where they are  
• Experience difficulties with less complex mental calculations e.g. counting backwards from 20 by 2’s  
• Need assistance choosing appropriate clothing for the occasion or the season  
• Generally need no support with eating or toilet routine  
• Generally recall substantial information about themselves and they know their own name and the names of their spouse and children |
| **STAGE 6 Severe cognitive decline** | Memory continues to deteriorate, radical personality changes may appear, and extensive assistance is needed with daily activities. At this stage, individuals may:  
• Lose significant awareness of their surroundings as well as recent experiences and events  
• Have problems to recall their personal history, although they usually remember their own name  
• Occasionally forget the name of their spouse or primary caregiver, but generally can distinguish between familiar and unfamiliar faces  
• Require assistance with getting dressed appropriately. Without help, they may make such errors as putting shoes on wrong feet or pyjamas over daytime clothes  
• Need assistance with toilet routine  
• Experience increasing incidents of urinary or fecal incontinence  
• Tend to wander and get lost  
• Experience significant personality changes and behavioural symptoms  
• Experience disruption of their usual sleep/waking pattern |
| **STAGE 7 Very severe cognitive decline** | This is the final stage in the disease progression. Individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement. At this stage individuals may:  
• Lose their ability to produce recognizable speech, although words or phrases my occasionally be articulated  
• Need help with eating and toilet routine and general incontinence is existent  
• Lose their ability to walk without assistance, to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles become rigid. Impaired swallowing is experienced |

The Reisberg seven-stage model of Alzheimer’s disease suggests that Alzheimer’s disease progresses gradually. The model focuses on the symptoms of Alzheimer’s
disease and how it affects quality of life as the disease progresses from very mild to very severe cognitive decline.

Although both staging models of Alzheimer’s disease provide a useful framework for clinicians, families and caregivers, individual differences in symptom presentation and disease progression should be considered when applying them in practice.

2.6.6 Diagnosis of Alzheimer’s disease
The detection of Alzheimer’s disease early in its clinical course can be quite challenging, while its identification later in its development is often more apparent. There are no definite diagnostic tests for Alzheimer’s disease and, in the vast majority of cases; the disease is diagnosed by symptoms and by means of clinical examination and neuropsychological assessment (Minati et al., 2009:102). It often requires a multi-disciplinary approach (Qadi & Feldman, 2007:41). These tests help exclude other conditions that might cause the signs and symptoms of Alzheimer’s disease (Greeff, 2009:364) such as multi-infarct dementia, vitamin deficiency, tumours, systemic illnesses and depression (Rathmann & Conner, 2007:1501). The absence of diagnostic tests for Alzheimer’s disease often impedes the early diagnosis of the disease, as symptoms are not reported until they become problematic (Marseille & Silverman, 2006:123). In addition, the detection of Alzheimer’s disease may be more difficult in cultural and socio-economic settings where memory loss is often considered normal in old age, where older persons face fewer cognitive demands in everyday life, or where low educational levels pose greater challenges to objective cognitive assessment (American Psychiatric Association, 2013). This is specifically reported in South Africa where very few neuropsychological measures have been properly validated for use among persons who are not Caucasian, do not speak English, or lack high school education (Manly as quoted by Mosdell, Balchin & Ameen, 2010:250).

An examination of a person with psychiatric problems begins with the attempt to recognise the individual pattern of symptoms and experiences that leads to the establishment of a specific psychiatric diagnosis. This diagnosis should be expressed in particular terminology according to a recognised classification system (Mace & Rabins, 2011:13; Pretorius, 2001:7). The Diagnostic and Statistical Manual
of Mental Disorders is such a classification system that is commonly used by clinicians. Section 2.6.6.1 describes the diagnostic criteria for Alzheimer’s disease according to the Diagnostic and Statistical Manual of Mental Disorders. Recent medical advancements have seen the development of biomarkers to supplement the symptom-based diagnosis of Alzheimer’s disease. The use of biomarkers is discussed in section 2.6.6.2.

2.6.6.1 Diagnostic criteria for Dementia and Alzheimer’s disease as specified in the Diagnostic and Statistical Manual of Mental Disorders – 5th edition (DSM 5)

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is a system developed by the American Psychiatric Association to define a group of discrete disease entities, each characterised by a distinct pathology and etiology. Clinicians often refer to it as the DSM-V, which refers to the fifth edition of the manual. The DSM-V incorporates dementia into the diagnostic categories of major and mild neurocognitive disorders. To meet the DSM-V criteria for major neurocognitive disorder, an individual must have evidence of significant cognitive decline that interferes with independence in everyday activities. For mild neurocognitive disorder, an individual must have evidence of modest cognitive decline, but the decline does not interfere with everyday activities. For both major and mild cognitive disorders, DSM-V instructs physicians to specify whether the condition is due to Alzheimer’s disease, frontotemporal lobar degeneration, Lewy body disease or a variety of other conditions (Alzheimer’s Association, 2014:5).

The American Psychiatric Association (2013) provides the following DSM-V diagnostic criteria for major or mild neurocognitive disorder due to Alzheimer’s disease:

Table 2.4: Diagnostic criteria for major or mild neurocognitive disorder due to Alzheimer’s disease (American Psychiatric Association, 2013)

| A. | The criteria are met for major or mild neurocognitive disorder |
| B. | There is insidious onset and gradual progression of impairment in one or more cognitive domains (for major neurocognitive disorder, at least two domains must be impaired) |
| C. | Criteria are met for either probable or possible Alzheimer’s |
For major neurocognitive disorder:

Probable Alzheimer’s disease is diagnosed if either of the following is present; otherwise, possible Alzheimer’s disease should be diagnosed

1. Evidence of a causative Alzheimer’s disease genetic mutation from family history or genetic testing

2. All three of the following are present:
   a. Clear evidence of decline in memory and learning and at least one other cognitive domain (based on detailed history or serial neuropsychological testing)
   b. Steadily progressive, gradual decline in cognition, without extended plateaus
   c. No evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological, mental, or systemic disease or condition likely contributing to cognitive decline)

The DSM-V provides criteria for making a diagnosis of Alzheimer’s disease and makes provision for the diagnosis for both probable and possible Alzheimer’s disease, based on the gradual memory and cognitive decline of the individual.

2.6.6.2 The use of biomarkers in diagnosing Alzheimer’s disease

With the recent emergence of biomarkers (a biological factor that can be measured to indicate the presence of absence of disease, or the risk of developing a disease), to provide some indication of pathological decline, there has been a shift in routine diagnostic practice from the traditional understanding that Alzheimer’s disease is reflected in the presence of dementia symptoms (e.g. memory impairment and cognitive decline) to an acknowledgement of Alzheimer’s disease as a pathological disease that develops years before the first presentation of clinical symptoms (Gaugler, Kane, Johnston & Sarsour, 2013:338). Levels of certain proteins in fluid (e.g. levels of amyloid beta [Aβ] and tau in the cerebrospinal fluid [CSF] and blood) are among several factors being studied as possible biomarkers for Alzheimer’s disease (Alzheimer’s Association, 2013:211; Holtzman et al., 2011:2). Table 2.5 provides a summary of the most frequently used biomarkers in the diagnosis of Alzheimer’s disease.
Table 2.5: Biomarkers used in the diagnosis of Alzheimer’s disease (Gaugler et al., 2013:338)

<table>
<thead>
<tr>
<th>BIOMARKER TYPE</th>
<th>APPLICATION</th>
</tr>
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<tbody>
<tr>
<td>Positron emission tomography (PET)</td>
<td>PET is used to identify regions in the brain where 18F-fluorodeoxyglucose (FDG) uptake is impaired.</td>
</tr>
<tr>
<td>Neuro-imaging</td>
<td>Neuro-imaging provides visual displays to examine changes in the size of, structure of, or activity in the brain (e.g. cerebral atrophy and decreased uptake of glucose).</td>
</tr>
<tr>
<td>Single-photon emission computed tomography (SPECT)</td>
<td>SPECT is used to assess regional blood flow as a reduction in oxygen use or blood flow is apparent in regions of the Alzheimer brain.</td>
</tr>
<tr>
<td>Computerised tomography (CT)</td>
<td>CT uses a non-invasive scanning procedure to generate a two-dimensional brain image.</td>
</tr>
<tr>
<td>Magnetic Resonance Imaging (MRI)</td>
<td>MRI relies on radio waves and magnetic fields to generate both two- and three-dimensional images of the brain.</td>
</tr>
<tr>
<td>Electroencephalography (ECG)</td>
<td>ECG is used to examine neuronal activity of the cerebral cortex and to examine the brain function in dementia, cognitive ageing and various neurological disorders.</td>
</tr>
<tr>
<td>Lumber puncture</td>
<td>Lumber punctures are used to examine whether elevated concentrations of total tau proteins are present and to examine changes in cerebrospinal fluid.</td>
</tr>
</tbody>
</table>

Alzheimer’s disease progresses gradually and symptoms may only appear later during its course. Although there is no specific diagnostic test for Alzheimer’s disease, the DSM-V criteria and clinical biomarkers provide useful tools for clinicians to make a diagnosis of the disease and should be used to complement each other in practice.

2.6.7 Management of Alzheimer’s disease

Alzheimer’s disease is a progressive and irreversible illness that is set to create one of the world’s major socio-economic health care burdens in the near future. This accentuates the urgency of seeking effective therapeutic interventions for patients with Alzheimer’s disease. Current therapeutic approaches for Alzheimer’s disease have been developed to relieve its symptoms and to modify its course (Qadi, Assaly

The symptomatic treatments of cognitive and associated behavioural problems hold potential to improve the quality of life of the patients, and their caregivers, and reduce the resources needed to provide adequate institutional and home health care (Brookmeyer et al., 2007:186; Rogan & Lippa, 2002:12). The primary goal of treating patients with Alzheimer’s disease is to improve their quality of life, and maximise functional performance by enhancing cognition, mood and behaviour (Heggie, Morgan, Wong, Karunanayake & Beever, 2011:522; Rogan & Lippa, 2002:12). Unfortunately, in Africa, medical doctors and nurses, largely at the primary care level, lack awareness of and training in diagnosing and treating dementia, and simply ascribe the symptoms to old age. Nurses often inform demented patients that no medications are available for their particular condition, without referring them for further investigation (Kalula & Petros, 2011:32). In a study conducted in rural Limpopo, Mavundla, Toth and Mphelane (2009:362) found that persons with mental illness are not only rejected by the community, but also by some health care professionals, being uninterested and apathetic in assisting and treating them. Borochowitz (2011:32) agrees by citing that it is no secret that older persons with Alzheimer’s disease are not a health priority in South Africa, as they are in many developed countries. South Africa is plagued with many other social and economic ills, including poverty and unemployment, not to mention the burden of diseases such as HIV and AIDS and tuberculosis. Older persons with dementia often receive inadequate and insufficient attention to their growing needs.

2.6.7.1 Pharmacological treatment

The continuous increase in life expectancy, resulting in a larger number of persons with Alzheimer’s disease, has led to an enormous increase in research focussed on the development of drugs for the prevention of the disease. Despite all scientific efforts, there are no effective pharmacotherapeutic options for prevention and treatment of Alzheimer’s disease. Current available treatments are only symptomatic in nature, trying to counterbalance the neurotransmitter disturbance and to control the psychotic and behavioural symptoms of the disease (Kalaria,
The United States Food and Drug Administration has approved five drugs that temporarily improve symptoms related to the disease. These drugs include tacrine, donepezil, galantamine and rivastigmine. None of the current available treatment changes the underlying course of Alzheimer’s disease; still, they offer options for treating the cognitive impairment associated with the disease (Cavanaugh & Blanchard-Fields, 2006:139). However, a number of treatment strategies are currently researched that may have the potential to change the course of the disease (Alzheimer’s Association, 2012:134).

2.6.7.2 Non-pharmacological treatment
Reiman and Caselli (1999:195) argue that non-medication treatment strategies, such as cognitive training and behavioural interventions, are often more important than medications in the management of Alzheimer’s disease. These techniques include the provision of a stable environment and daily routine, the scheduling of meals, bathroom visits, and night-time fluid intake in a manner that maximises nutrition, minimises incontinence, and reduces awakenings, the provision of adequate sensory stimulation and the use of practice hygiene techniques.

Although no non-pharmacological interventions have demonstrated to alter the course of Alzheimer’s disease, some of them are used with the goal to maintain cognitive function, help the brain compensate for impairments, improve quality of life or reduce behavioural symptoms such as aggression, sleep disturbances, apathy, wandering and depression (Alzheimer’s Association, 2013:214). A combination of pharmacological and non-pharmacological treatment can alleviate the symptoms of Alzheimer’s disease and improve the quality of life of the individual. The crucial role of the Alzheimer’s caregiver will be discussed in the next section.

2.7 Caregiving in the context of Alzheimer’s disease

When older persons are confronted with changes in health and daily functioning, they most frequently turn to family members, typically their spouse or older children,
for care and support. Family members who provide such care are likely to be middle-aged and older women, many of whom are caring simultaneously for children or multiple generations of elders (Roberto & Jarrott, 2008:100). Unlike most other chronic diseases, people with dementia can develop needs for care in the early stages of the disease and become increasingly reliant on caregivers throughout the course of the disease (Alzheimer's Disease International, 2013:25).

In the US, an estimate of 52 million adults care for an ill or disabled family member of whom almost 9 million are caregivers for a family member with dementia (Noyes, et al., 2010:9). In less developed countries, family members are the primary caregivers to older relatives with dementia. A recent study in South Africa found that 79 percent of a memory clinic’s dementia clients were being cared for by family members (Kalula et al., 2010:450; Kalula & Petros, 2011:33). When considering the significant increase in the burden of dementia care in developing countries (Kalula & Petros, 2011:37); the distinct unavailability of residential care facilities in South African rural areas (Department of Social Development, 2010; Goins et al., 2009:140); and the shift from institutional care to community-based care as framed by government policies, such as the Older Persons Act 13 of 2006 and Mental Health Care Act 17 of 2002, it can be gathered that the vast majority of persons with dementia and Alzheimer’s disease are cared for by family caregivers in the community, with health care professionals, according to Mavundla et al. (2009:358), playing a secondary role.

Providing care to an older family member with dementia often presents multiple challenges. A number of prevailing factors influences the caregiving experience. It is well documented in literature that caring for a person with dementia is associated with physical illness, emotional strain and mental health problems (Butler, 2008:1260; Coetsee, 2007:12; Ekwall & Hallberg, 2007:833; Noyes et al., 2010:9; WHO, 2012:2-3). When the needs of caregivers are not effectively met, caregiver burden and burnout often results (Bartfay & Bartfay, 2013:99). Unmet needs are particularly common among caregivers of people with dementia compared with other caregivers (Raivio, Eloniemi-Sulkava, Laakonen, Saarenheimo, Pietilä, Tilvis & Pitkälä, 2007:361). Note, however, that caregiving outcomes may vary among caregivers from different racial groups (Connell, Janevic & Gallant, 2001:181; Sun et
al., 2010:291) and that recent studies have documented positive outcomes associated with dementia caregiving (Lee & Choi, 2012:424; Mavundla et al., 2009:355). Furthermore, the caregiving experience may be influenced by culturally-based views and perceptions about the caregiving process (Ivey et al., 2012:807) and stigmatisation and social ostracism of individuals with mental illness and their families (Mavundla et al., 2009:363).

2.7.1 Caregiving and the Alzheimer’s disease patient

With the ageing of the population, an increased number of older persons are diagnosed with Alzheimer’s disease and will be cared for by a family member at home (Connell et al., 2001:179). These family caregivers must, themselves, come to terms with the disease. Juozapavicicius and Weber (2001:12) as well as Kalula and Petros (2011:33) argue that, although any form of caregiving is a demanding process, Alzheimer’s caregivers can be differentiated from other caregivers through the prevalence and severity of problems faced by Alzheimer’s caregivers as a whole. The same authors explain that perhaps the most significant problem experienced by Alzheimer’s caregivers is the lack of reciprocity that exists in their situation. “In other forms of caregiving, the care recipient may often attempt to reciprocate the care they receive through words and actions of gratitude, helpfulness, cooperation and support. In contrast, with Alzheimer’s caregiving, by the middle and late stages of the disease, where care is most intensive, the recipient can no longer express gratitude or helpfulness. Instead, the care recipient is often full of anger and resentment toward the caregiver and becomes belligerent, uncooperative, and even violent.” This imbalance may lead to higher levels of anger, frustration and resentment in the Alzheimer’s caregiver.

Alzheimer’s disease is a progressive and chronic disease, and therefore it is inevitable that the affected person will become dependent on care. Alzheimer’s Association (2011:220) and Alzheimer’s Disease International (2013:25) suggest that the progression in needs for care is linked to deterioration in cognition, function and behaviour throughout the early, middle and final stages of the disease. Alzheimer’s Association (2014:30) proposes that, on average, American caregivers provide between 16 and 30 hours of care per week. A less recent study conducted by Davis, Marin, Kane, Patrick, Peskind, Raskind and Puder as quoted by McCarron, Gill,
Lawlor and Bregler (2002:265) reported that the estimated time spent assisting the person with dementia in their day-to-day activities of living averaged 11 hours over a 24-hour period. Table 2.6 summarises the characteristic features and associated caregiving tasks of each stage in the progression of Alzheimer’s disease.

*Table 2.6: Characteristic features of Alzheimer’s disease and associated caregiving tasks during disease progression (Alzheimer’s Association 2011:220; Alzheimer’s Disease International, 2013:25)*

<table>
<thead>
<tr>
<th>STAGE</th>
<th>CHARACTERISTIC FEATURES</th>
<th>CAREGIVING TASKS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early stages</td>
<td>• Memory impairments&lt;br&gt;• Orientation difficulties in terms of time, place and people&lt;br&gt;• Difficulties in making decisions and managing personal finances&lt;br&gt;• Difficulties in carrying out household tasks&lt;br&gt;• Affected mood and behaviour, including loss of motivation and interest, symptoms of depression and inappropriate anger outbursts</td>
<td>• Provide emotional support&lt;br&gt;• Remind person about events and tasks&lt;br&gt;• Provide assistance with instrumental activities such as managing finances, household chores and shopping&lt;br&gt;• Help with taking medication and following treatment recommendations</td>
</tr>
<tr>
<td>Middle stages</td>
<td>• Difficulties in communication&lt;br&gt;• Need for help with personal care and hygiene&lt;br&gt;• Unable to prepare food, clean or shop&lt;br&gt;• Behaviour changes, including wandering, repeated questioning, calling out, clinging, agitation and aggression&lt;br&gt;• Psychological disturbances such as delusions, hallucinations and sleep disturbances</td>
<td>• Increased and constant supervision&lt;br&gt;• Assistance with communication strategies&lt;br&gt;• Help with personal care and hygiene&lt;br&gt;• Help with transportation&lt;br&gt;• Increased help with activities of daily living such as food preparation, feeding, appropriate dressing, bathing and toileting&lt;br&gt;• Supervise person to avoid unsafe activities such as wondering and getting lost</td>
</tr>
<tr>
<td>Final stages</td>
<td>• Unaware of time and place&lt;br&gt;• Unable to recognise relatives, friends or familiar objects&lt;br&gt;• Unable to eat without help&lt;br&gt;• Severely restricted mobility and sometimes bed-bound</td>
<td>• Care, support and supervision are constant&lt;br&gt;• Full physical care has to be provided&lt;br&gt;• Deal with behavioural problems</td>
</tr>
</tbody>
</table>
It is clear that the intensity and complexity of the tasks associated with caring for the person with Alzheimer’s disease increases as the disease progresses from early to final stages, and therefore increases the demands on caregivers.

2.7.2 Demographic profile of the Alzheimer’s disease caregiver

Several research studies have described the demographic background of family caregivers of people with Alzheimer’s disease and other dementias (Gonzalez, Polansky, Lippa, Walker & Feng, 2011:528-536; Juozapavicius & Weber, 2001:11-20). Alzheimer’s Association (2013:221) refers to the findings of the 2010 Behavioural Risk Factor Surveillance System survey conducted in the United States of America. The survey found that 62 percent of caregivers of persons with Alzheimer’s disease and other dementias were female; 23 percent were 65 years of age and older; 50 percent had some college education or beyond; 59 percent were currently employed, a student or homemaker; and 70 percent were married or in a long-term relationship. In the study conducted by Juozapavicius and Weber (2001:14), the researchers established that the duration of providing care to persons with Alzheimer’s disease exceeded five years in 60 percent of caregivers. In another American-based study commissioned by the Alzheimer’s Association (2013:221) in 2009, the National Alliance for Caregiving found that 30 percent of caregivers had children younger than 18 years old living with them. Concerning ethnic and racial diversity in caregiving, the study found that a greater proportion of white caregivers assist a parent than caregivers or individuals from other ethnic/racial groups (54% vs 38%). On average, Hispanic and black caregivers spent more time caregiving (30 hours per week) than non-Hispanic white caregivers did (20 hours per week). Additionally, it was found that Hispanic (45%) and black (57%) caregivers are more likely to experience heavy burden from caregiving than whites (33%).

In a study conducted in Cape Town, to determine the profile and management of patients at a memory clinic, Kalula et al. (2010:450) found that of the 305 patients who visited the clinic between 2003 and 2008, 79 percent were cared for by family caregivers, 6 percent were institutionalised, and 74 percent of those who lived with family lived with a spouse and/or adult children. The ethnic distribution of the
patients was 64.9 percent coloured, 28.5 percent white, 6.6 percent black, and 2 percent Indian.

Although no specific studies was found that conclusively determined the demographic profile of Alzheimer’s caregivers in South Africa, Kalula and Petros (2011:33) explain that multi-generational co-residence is the norm in developing countries where family members are the primary caregivers to elderly relatives with dementia. Even young children may be primary caregivers to an afflicted grandparent or great-grandparent. However, Alzheimer’s Disease International (2009:55) warns that in many developing countries, the traditional family and kinship structures are threatened by social and economic changes that accompany economic development and globalisation, which can result in a decrease in the availability of family members that can help with the caregiving of their older relatives. These factors include the education of women and their increasing participation in the workforce, internal and international migration of employable family members, declining fertility rates and HIV/AIDS related deaths in Sub-Saharan Africa, resulting in elderly parents of deceased adult children without family support.

2.7.3 Impact of Alzheimer’s disease caregiving
Caring for persons with Alzheimer’s disease poses special challenges and the adverse outcomes associated with caregiving are well researched and documented in literature. Such caregiving is said to have an immense emotional, psychological, physical and financial impact on the caregiver, over an extended period of time (Black, Gauthier, Dalziel, Keren, Correia, Hew & Binder, 2010:808; Vitaliano, Young & Zhang, 2004:13) and affects all aspects of a person’s life (Roberto & Jarrott, 2008:102). Although Kalula and Petros (2011:33) are of the opinion that caregivers in developing countries are generally ill-prepared and ill-equipped for caregiving tasks, and are often unsupported, which results in high levels of care burden, very few studies have examined the outcomes associated with caregiving in less-developed countries (Mavundla et al., 2009:359) and more specifically in South African rural communities. This section provides an overview of the impact of caregiving on the physical, psychological and social wellbeing of the caregiver.
2.7.3.1 Physical impact of caregiving

For many caregivers, the demands of caregiving for a person with Alzheimer’s disease may result in increased risk of poor health themselves. Rabinowitz, Mausbach, Thompson and Gallaghar-Thompson (2007:947) note that caregiving is associated with insufficient sleep, a poor nutritional regimen and a lack of sufficient physical exercise, resulting in a decline in general health. A literature comparison indicating the most frequently reported and experienced physical health problems by caregivers is summarised in table 2.7.

Table 2.7: Physical health outcomes associated with Alzheimer’s caregiving

<table>
<thead>
<tr>
<th>CAREGIVER HEALTH PROBLEMS</th>
<th>SOURCE</th>
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</thead>
<tbody>
<tr>
<td>General decline in physical health</td>
<td>Alzheimer’s Association (2013:225); Brinda, Rajkumar, Enemark, Attermann and Jacob (2014:5); Coetsee (2007:47); Connell et al. (2001:179); Do, Norton, Stearns and Van Houtven (2013); Lahaie, Earle and Heymann (2012:252); Llanque and Enriquez (2012:24); Meyers (2003:153); O’Rourke and Tuokko (2000:390); Roepke, Mausbach, Patterson, Von Känel, Ancoli-Israel, Harmell, Dimsdale, Aschbacher, Mills, Ziegler, Allison and Grant (2011:59); Vitaliano et al. (2004:13)</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>Alzheimer’s Association (2013:22); Holland, Thomspon, Cucciare, Tsuda, Okamura, Spiegel, Rasgon and Gallagher-Thompson (2011:334); Lahaie et al. (2012:252); Llanque and Enriquez (2012:24); O’Rourke and Tuokko (2000:390); Roepke et al. (2011:59); Vitaliano et al. (2004:13)</td>
</tr>
<tr>
<td>Reduced immune function</td>
<td>Alzheimer’s Association (2013:225); Llanque and Enriquez (2012:54); Meyers (2003:15); Roepke et al. (2011:59); Vitaliano et al. (2004:13)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>Alzheimer’s Association (2013:225); Chattillion, Cegłowski, Roepke, von Känel, Losada, Mills, Patterson and Mausbach (2013:794); Roepke et al. (2011:59); Vitaliano et al. (2004:13)</td>
</tr>
</tbody>
</table>

In addition to the above-mentioned health outcomes, Alzheimer’s Association (2013:225) and Meyers (2003:153) report that Alzheimer’s caregivers are at greater
risk of mortality due to the stress associated with caregiving. It is evident that caregiving can negatively affect the health of caregivers, although the health outcomes may vary among caregivers, and are dependent on a number of factors, which are discussed in section 2.7.4.

2.7.3.2 Psychological impact of caregiving

It is generally accepted that caring for a person with Alzheimer’s disease is associated with high levels of stress and burden. Alzheimer’s Association (2011:221) argues that the close relationship between the caregiver and the impaired person, and the increasing levels of supervision and personal care needed, may particularly place caregivers at risk for psychological illness. The high levels of stress experienced by dementia caregivers can result in negative physical and mental health outcomes (Cheng, Lam, Kwok, Ng & Fung, 2012:71).

A large number of studies have investigated the psychological consequences of caregiving. Adams, Smythe and McClendon (2005:475); Akkerman and Ostwald (2004:117); Alzheimer’s Association (2013:223); Bauer, Maddox, Kirk, Burns & Kuskowski (2001:329); Theofilou (2012:2) and Vitaliano et al. (2004:14) cite that caregivers often experience a range of psychological symptoms, including, frustration, depression, anxiety, anger, guilt, somatic symptoms (e.g. insomnia, headaches, and stomach distress), isolation and conflicts in relationships. In a South African study led by Potgieter and Heyns (2006:560), it was found that the unpredictability of the course of Alzheimer’s disease, the increasing amount of care and supervision needed by the Alzheimer’s sufferer, and the limited resources of caregivers to deal with the day-to-day challenges associated with caregiving, contributed to the care burden of caregivers.

Although the negative outcomes associated with caregiving have been researched to a great extent, a growing body of literature has examined a wide range of positive outcomes. Connell et al. (2001:180) cite that these outcomes include enjoyment of the role, general wellbeing, positive affect, role gain, gratification, satisfaction, mastery, growth and meaning. Alzheimer’s Association (2013:223) adds that, besides satisfaction, caregiving is often associated with family togetherness.
In a study conducted among 1229 caregivers, Tarlow, Wisniewski, Belle, Rubert, Ory and Gallagher-Thompson (2004:439) found that most caregivers perceived their caregiving as providing them with a variety of positive and satisfying experiences. The caregivers reported that caregiving made them feel needed, useful and good about themselves. Most caregivers also reported that caregiving enabled them to develop a more positive attitude toward life, appreciate life more and strengthened their relationships with others.

It is evident that the psychological impact of caregiving affects individuals in different ways that are dependent on a number of factors. These factors are discussed in section 2.7.4.

2.7.3.3 Social impact of caregiving

In addition to the physical and psychological impact, providing care to the person with Alzheimer’s disease can further impact on the social functioning of the caregiver and - according to Aquirre, Hoare, Spector, Woods and Orrell (2014:31) - may lead to poor quality of life.

Caregiving often results in rearranged role patterns and relationships within the family system. Lai (2010:201) reports that balancing the caregiving role within one’s own lifestyle is commonly associated with stress and burden. Often caregivers have to simultaneously balance the roles of spouse, parent, breadwinner and care provider for older relatives. Lai further states that caregivers often have less time for their children, families, self-care and relaxation. These role conflicts increase their risk for role-overload (Pinquart & Sörensen, 2011:1) and result in a sense of identity loss in the caregiving role (Roberto & Jarrott, 2008:103). Caregiving may also disrupt existing relationship patterns and can result in interpersonal conflict or other signs of family dysfunction (Scharlach, Li & Dalvi, 2006:626).

When considering the intensive and time-consuming tasks associated with Alzheimer’s caregiving, it can result in restricted social activities, strained interactions and social isolation, where caregivers lack social and emotional support (Bachner, Karus & Raveis, 2009:1018; Gaugler, Anderson, Leach, Smith, Schmitt & Mendiondo, 2004:377).
Caregiving in the context of Alzheimer’s disease may have a negative impact on the economic wellbeing of the caregiver. Roberto and Jarrott (2008:102) refer to a study conducted by the National Alliance for Caregiving, which found that 59 percent of family caregivers juggle employment with caregiving responsibilities in order to meet their own financial obligations and the cost of caring for their relatives. Wakabayashi and Donato (2005:467) argue that caregiving may compete with employment and create losses in working hours and earnings.

2.7.4 Factors influencing the impact of caregiving
Several factors have been identified that have an effect on the caregiving experience. The most significant factors described in literature are discussed in this section.

2.7.4.1 Knowledge of Alzheimer’s disease
People have varying knowledge about Alzheimer’s disease. Carpenter, Zoller, Balsis, Otilingam and Gatz (2011:121); Hughes, Tyler, Danner and Carter (2009:109) and Washington, Meadows, Elliot and Koopman (2011:40) refer to various studies which found that family caregivers demonstrated poor knowledge about disease epidemiology and etiology. However, the findings showed that they were more knowledgeable than non-caregivers were. This points to the fact that the caregiving experience enhances knowledge about Alzheimer’s disease. Literature emphasises that knowledge is an important enabler for behaviours, and lack of knowledge is an impediment to appropriate help seeking (Jang, Kim & Chiriboga, 2010:419). Edwards, Cherry and Peterson (2000:27) caution that misconceptions and ignorance about Alzheimer’s disease carry serious consequences for caregivers and the victims themselves, and can lead to feelings of isolation and abandonment (Vellone, Piras, Ventunni, Alvaro & Cohen, 2012:52).

2.7.4.2 Stigma and cultural beliefs
Dementia and Alzheimer’s disease are perceived differently in different parts of the world. Alzheimer's Disease International (2012:2) states that the disease is considered by some as a normal part of ageing and by others as a mental illness, an irreversible brain disease or even as something metaphysical linked to supernatural or spiritual beliefs. Differences in cultural norms and beliefs often appear to influence the understanding of dementia (Belgrave, Allen-Kelsey, Smith & Flores,
and what is perceived as psychotic in one culture may be acceptable in other cultures (Faison & Armstrong, 2003:227).

Stigma associated with Alzheimer's disease is indicated in literature as having a significant effect on caregivers. Montoro-Rodriquez, Kosloski, Kercher and Montgomery (2009:196) and Werner, Goldstein and Buchbinder (2010:159), for example, explain that the inappropriate behaviour of Alzheimer's persons in social settings often causes social embarrassment and is regarded as one of the most significant stressors for caregivers and contributes to caregiver depression. This frequently results in persons suffering from Alzheimer's disease being isolated or hidden from the community and prevents people from acknowledging the symptoms and obtaining the help they need (Alzheimer's Disease International, 2012:2-3).

In some African cultures, dementia symptoms are perceived as a sign of possession by evil spirits (Botsford et al., 2011:443; Jorm, 2000:397; Sorsdahl, Flisher, Wilson & Stein, 2010:288). Likewise, in South Africa, Alzheimer's disease is not as yet commonly accepted by African people as a disease. Benade (2012:76) and Borochowitz (2011:32) explain that in rural areas, belief in ancestral powers and witchcraft is common, and communities generally see older persons who display demented behaviour as having been placed under evil spell either by their ancestors or by a witch. Benade (2012:76) and Oggunniyi, Baiyewu, Gureje, Unverzagt & Hendrie (2006:260) report on a number of cases of older persons showing strange behaviour being burnt or murdered by their communities, because they think they are bewitched. Older persons displaying Alzheimer’s related behaviour, and who are dark in complexion, are particularly at risk, according to Benade (2012:76), as they are seen as being able to blend into the night to do their evil deeds. This often results in, according to Gureje (2007:12), alienation of the mentally ill.

The use of traditional healing is a common practice in rural communities as opposed to Western medicine and, according to Peltzer (2001:4), is the first choice of treatment for many South Africans. Mbwayo, Ndetei, Mutiso and Khasakhala (2013:134) assert that in developing countries, up to 80% of the population depends on traditional medicines to meet their health care needs. Kalula et al. (2010:229)
state that black South Africans often resort to complementary medicine or traditional healing for the treatment of Alzheimer's disease. Mavundla et al. (2009:359) support this view by explaining that people living in rural communities often have negative attitudes towards medication and turn to traditional medicine, such as faith healers and witchdoctors. In addition, families often feel that their relatives cannot be cured and use herbs instead of medication. Hugo, Boshoff, Traut, Zungu-Dirwayi and Stein as quoted by Mavundla et al. (2009:359) mention that this situation is further exacerbated by misinformation and stigma surrounding mental illness in South African rural areas where traditional explanatory models are still prevalent.

2.7.4.3 Gender

Women provide the majority of unpaid care for dependent older persons. A number of large-scale studies have found that that women constitute a majority of the informal caregivers of adults in need of assistance (Lahaie et al., 2012:245). Toribio-Diaz, Medrano-Martinez, Moltó-Jordá and Beltrán-Blasco (2013:98) explain that society assumes that women are to be responsible for caring for dependent people, based on a series of arguments regarding the way they are raised, the values they supposedly embrace, and their role in society. In the United States of America, black caregivers are typically unpaid females who are caring for a parent, in-law, or other elderly relative in the caregiver’s home (Llanque & Enríquez (2012:23). Very often, these caregivers are older adults with one or more chronic health condition (Bauer et al., 2001:329).

Research on gender differences in caregivers suggests that the effects of caregiving differ between women and men. Most studies reported that female caregivers experienced more depressive symptoms, anxiety and general psychiatric symptoms than their male counterparts (Schoenmakers, Buntinx & Delepeleire, 2010:196). It was also found that women spend more time on caregiving tasks than men (Connell et al., 2001:180) and often combine their caregiving responsibilities with regular jobs (Lahaie et al., 2012:245). In addition, Villareal-Renya, Salazar-Gonzalez, Cruz-Quevedo, Carrillo-Cervantes and Champion (2012:974) cite that wives of male partners with Alzheimer’s disease report a greater subjective burden, feelings of hostility and anger and lower levels of satisfaction and participation in social activities.
than husbands with Alzheimer's disease partners. Women are thus particularly vulnerable to the negative outcomes associated with caregiving.

2.7.4.4 Level of educational attainment
Marks, Lambert, Jun and Song (2008:363) assert that less education might be an exacerbating risk factor for caregivers, who might feel less comfortable with negotiating the informational systems of health care and social services that might accompany care for a person with Alzheimer's disease. However, Lahaie et al. (2012:248) point out that no studies have been conducted to examine the relationship among caregivers’ educational attainment, the extent of their caregiving, and its impact on their own wellbeing.

2.7.4.5 Demographic location
Rural areas are often associated with limited access to health care and social services compared to urban areas and therefore the challenges faced by Alzheimer's caregivers in rural areas are different to those in more developed urban areas. Edelman, Kuhn, Fulton and Kyrouac (2006:226) report that rural American caregivers are faced with a unique combination of factors that create disparities in health care and social services. They cite that less than 10 percent of physicians practice in rural areas and that the lack of health care services contributes to poorer health and higher morbidity and mortality rates. Furthermore, economic, cultural, social and education differences present major challenges in coping with chronic medical conditions such as Alzheimer's disease. Kosberg, Kaufman, Burgio, Leeper and Sun (2007:6) report that older persons in rural areas often experience unaddressed physical and mental health problems. They furthermore note that rural areas often lack Alzheimer's disease services.

In a study conducted by Innes, Blackstock, Mason, Smith and Cox (as cited in Innes, Morgan & Kostineuk, 2011:36) in rural Scotland, the primary gaps identified were lack of appropriate services, lack of transport, respite services, support for caregivers, home care and day care as well as stigma and isolation. However, the caregivers described rural areas as healthy places and the people as resilient and self-sufficient, where personal relationships with service provider’s enhanced individualised care, and informal support networks reduced the burden of care.
2.7.4.6 Religion

Religion may help to alleviate the impact of stress on the caregiver. Heo and Koeske (2011:583) highlight the importance of religion and spirituality as resources for coping with stressful life events and argue that religiosity has been associated with improved mental health in people under stress. The same authors examined the relationship between religion and coping in 642 Alzheimer’s caregivers and found that religious coping resulted in lower caregiver burden and thereby reducing depression.

Other research studies compared African-American and white caregivers of persons with Alzheimer’s disease and found that African-Americans were more likely to obtain support from their pastors/church than white caregivers and that African-American caregivers used religious strategies more than whites as a coping mechanism (Nightingale, 2003:381). Dilworth-Anderson, Williams and Gibson as quoted by Heo and Koeske (2011:583) assert that non-white Americans tend to cope with the difficulties of caregiving using prayer, faith in God, religion and emotional support from church.

2.7.4.7 Health behaviours

The immense demands of Alzheimer’s caregiving may result in caregivers neglecting their own needs for sleep, proper nutrition and health care. Castro, King, Housemann, Bacak, McMullen and Brownson (2007:88) and Shanks-Mcelroy and Strobino (2001:168) explain that such neglect can result in caregiver fatigue, exhaustion and other physical health problems such as impairment of the immune system and malnutrition. Negative health behaviours do not only influence the caregiver’s health, but can also compromise the caregiver’s ability to provide care to the person with Alzheimer’s disease (Rabinowitz, Saenz, Thompson & Gallagher-Thompson, 2011:310). Moreover, neglecting their own health may worsen pre-existing illnesses or increase vulnerabilities to new health problems (Son, Erno, Shea, Femia, Zarit & Parris Stephens, 2007:873). On the other hand, Castro et al. (2007:89) observe that little is known about health habits specifically among caregivers residing in rural areas.
2.7.4.8 Social support

Social support is a commonly reported resource for confronting difficult circumstances (Wilks, 2009:2007) and is a critical variable in how well Alzheimer’s caregivers cope with the duties of caregiving and determine their wellbeing (Lee & Choi, 2012:424). Pequegnat (2002:11) distinguishes between functional and structural components of social support. Functional support refers to perceived availability, actual receipts, adequacy, reciprocity and satisfaction. Structural support refers to sources of support, size of the support network and links between network members. Sources of structural support include family members, friends, healthcare providers and other formal resources such as support groups and churches.

The importance of social support is described by Kerlin, Bell and Noah (2001:177) and Pillemer and Suitor (2002:172) who found that support by friends and family members, Alzheimer-specific support groups and professional health care providers, lead to more favourable outcomes in both mental and physical health of the caregiver and that a lack of support leads to negative outcomes. Lee and Choi (2012:424) refer to various studies which found that social support improves the mental health of caregivers, buffers the negative effect of caregiving and reduces caregiving related stressors. The strong relationship between social support and caregiver burden emphasises the importance of support groups for caregivers as a means of reducing stress (Meyers, 2003:155).

Rural caregivers are more likely to use informal support systems compared to their urban counterparts, whereas those residing in urban areas tend to use formal support services more often (Goins et al., 2009:165). The effect of caregiving on the Alzheimer’s caregiver is thus dependent on various factors, which may either aggravate or alleviate caregiver burden.

2.7.5 Caregiver interventions

Many families live with older persons who have Alzheimer’s disease and are the primary caregivers responsible for their quality of life. However, research indicates that family caregivers often lack the knowledge to carry out proper caregiving and are overwhelmed by the immense caregiving stress. Aggravating the situation, families rarely seek community support as they are not aware of available services
(Kwok, Lam, Yip & Ho, 2011:288). To help these families, health and social care professionals have the responsibility to link Alzheimer’s sufferers and their families with available support services and caregiver interventions in the community. Vellone et al. (2012:48) are of the opinion that skills training could improve the quality of life in caregivers.

Lindgren as cited in Bartfay and Bartfay (2013:99-100) defines a caregiving career, based on the lived experiences of caregivers looking after a family member with Alzheimer’s disease as consisting of the following three stages: encounter, enduring and exit. These stages provide professionals with important information for the development of effective caregiver intervention strategies. The encounter stage is characterised by rapid and major adjustment to the family’s normal patterns and routines and calls for information about the disease process and how to provide safe and effective care. The enduring stage is defined as the heavy duty caregiving phase, and is regarded as chronic and long term in nature. This stage is characterised by the need to prevent caregiver burden by providing supportive interventions and coping skills. The exit stage occurs when the caregivers’ coping skills are no longer effective and external help is needed to meet the health care needs of the person with Alzheimer’s disease. Such interventions include institutional care and home care by external health care professionals.

Several caregiver intervention strategies have been developed with the aim to ameliorate negative aspects of caregiving and to improve the health and wellbeing of Alzheimer’s caregivers. Alzheimer’s Association (2014:40) provides the following summary of the types and focus of these interventions.
Table 2.8: Type and focus of caregiving interventions (Alzheimer’s Association, 2014:40)

<table>
<thead>
<tr>
<th>TYPE OF INTERVENTION</th>
<th>DESCRIPTION</th>
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<tbody>
<tr>
<td>Case management</td>
<td>Provides assessment, information, planning, referral, care coordination and/or advocacy for caregivers</td>
</tr>
<tr>
<td>Psycho-educational</td>
<td>Includes a structured programme that provides information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease. This includes lectures, discussions and written materials and is led by professionals with specialised training</td>
</tr>
<tr>
<td>Counselling</td>
<td>Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning</td>
</tr>
<tr>
<td>Support groups</td>
<td>Less structured than psycho-educational or therapeutic interventions. Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of social isolation</td>
</tr>
<tr>
<td>Respite care</td>
<td>Planned, temporary relief for the caregiver through the provision of substitute care such as adult day services and in-home or institutional respite for a certain number of weekly hours</td>
</tr>
<tr>
<td>Training of the person with dementia</td>
<td>Memory clinic or similar programmes aimed at improving the competence of the care recipient, which may also have a positive effect on the caregiver</td>
</tr>
<tr>
<td>Psychotherapeutic approaches</td>
<td>Involves the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive-behavioural therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviours to deal with caregiving demands, and fostering activities that can promote caregiver wellbeing)</td>
</tr>
<tr>
<td>Multicomponent approaches</td>
<td>Intensive support strategies that combine multiple forms of interventions, such as education, support and respite into a single, long-term service (often provided for 12 months or more)</td>
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The burden of care associated with Alzheimer’s caregiving can be reduced by providing a range of caregiver interventions. In addition, such interventions can enhance the physical, social and emotional wellbeing, resulting in an improved quality of life of caregivers and facilitate their adaptation in the caregiving process. It is therefore imperative to work with the caregivers themselves in order to enhance their skills to manage an immensely challenging situation and to alleviate their emotional distress.
2.8 Social work and dementia care

Dementia sufferers and their families are often in need of social work services to cope with the demands of providing care to the persons with dementia. In this regard, Moore and Jones (2012:1) state that dementia has become a high priority for health and social care in recent years. Greene (2011:7) stresses that the increased number of older adults needing social services is a critical societal issue. Damron-Rodriquez, Lawrance, Barnett and Simmons (2006:140) emphasise the demand for social workers with the specialised knowledge and skills necessary to meet the needs of a rapidly growing ageing population. In addition, social work is one of the key professions identified for the interdisciplinary approach to services for older persons and their families (Damron-Rodriquez, Goodman, Ranney, Min & Takahashi, 2013:235).

Working with complex individuals and their families, places social workers in pivotal roles to support and empower their clients to engage in care when facing complex circumstances (Findley, 2014:84). Social work’s significant contributions to care can foster meaningful improvements in the quality of life for people with dementia and their families (Kaplan & Andersen, 2013:174-175). Crampton (2011:314); Gardner (1993:16) and Kaplan and Berkman (2011:364) are of the opinion that the need for social workers to acquire specialised knowledge and skill in gerontology and dementia care will continue to grow as the population is ageing and the incidence of dementia increases. Kane in Staples and Killian, 2012:332 states that experience in working with persons with dementia, will increase the skill and competency of social workers to deal with the needs of the older population.

Berkman (as quoted by Damron-Rodriquez et al., 2006:143) provides the following definition of geriatric social work.

Professionally responsible intervention to (1) enhance the developmental, problem solving and coping capacities of older people and their families; (2) promote the effective and human operating of systems that provide resources and services to older people and their families; (3) link older people with systems that provide them with resources, services and opportunities; and (4) contribute to the development and improvement of social policies that support persons throughout the lifespan.
This definition of geriatric social work thus encompasses direct practice, community organisation and policy levels of social work. Concerning the role of the social worker working in the field of gerontology, the National Association of Social Workers (2014) maintains that social work practice with older persons encompasses a broad range of functions. Whether working in micro or macro settings, the primary goal of the social worker is to address the specific challenges of the ageing process by promoting independence, autonomy, and dignity in later life. Social workers in gerontology must be knowledgeable about unique legislation, policies and social programmes that affect older persons. In addition, they must be knowledgeable about the aging process, the issues older persons, and their caregivers’ face, adept at accessing resources for clients, and strong advocates who champion the rights of the elderly.

The National Association of Social Workers (2014) further states that social workers specialising in gerontology possess a variety of knowledge and skills necessary for working with older persons. This includes assessment of older persons’ needs and functional capacity and expertise regarding physical and mental health issues, case and care management, long-term care, elder abuse, quality of life issues, service planning and advance care planning, clinical practice, and administration.

The social worker specialising in social work in health care and specifically in geriatrics and gerontology is thus well positioned to provide a range of services to older persons suffering from dementia, their families, and caregivers within a multidisciplinary team.

2.9 Summary

Dementia refers to a number of diseases that is characterised by memory impairment and a decline in cognitive abilities that primarily affects older persons. Alzheimer's disease is the most common form of dementia and is characterized by progressive psychological, behavioural and personality changes. Sixty to 90 percent of all dementias can be attributed to Alzheimer's disease. The incidence of Alzheimer's disease increases with age and poses serious implications for an older growing population.
The exact cause of Alzheimer’s disease remains to be unknown. What is clear is that the disease is associated with structural changes in the brain resulting in the death of neurons. Various hypotheses have been formulated to understand the etiology of Alzheimer’s disease. In addition, certain modifiable and non-modifiable factors have been identified that increase the risk of individuals to develop Alzheimer’s disease, with progressing age being the most significant risk factor.

Various staging systems have been developed to describe the patterns of symptom development in individuals with Alzheimer’s disease. The three-stage model and the seven-stage model indicate the subtle onset and progressive nature of Alzheimer’s disease.

The absence of diagnostic tests for Alzheimer’s disease makes the early detection of the disease challenging for clinicians. Largely, Alzheimer’s disease is diagnosed by the manifestation of symptoms, clinical examinations and neuropsychological assessment. The *Diagnostic and Statistical Manual of Mental Disorders* provides useful criteria for diagnosing Alzheimer’s disease. The recent development of biomarkers contributes to the early detection of Alzheimer’s disease.

Alzheimer’s disease is a progressive and irreversible illness. A number of therapeutic approaches have been developed to alleviate the symptoms and modify the course of the disease. Interventions include both pharmacological treatment and behavioural interventions.

Alzheimer’s disease and caregiving cannot be separated, as most persons with Alzheimer’s disease will become care dependent during the progression of the disease. The majority of these caregivers are family members. Providing care to a person with Alzheimer’s disease is challenging, and often results in caregiver burden as the caregiving tasks intensify with disease progression. Conversely, positive caregiving outcomes have been reported. Consistent with the ecosystems perspective, various factors have been identified that influence the impact of caregiving on the caregiver. In line with these factors, interventions have been developed to assist caregivers in providing care to persons with Alzheimer’s disease.
As dementia and Alzheimer’s disease are becoming a global epidemic, sufferers, their families, and caregivers are often in need of social work services to cope with the demands of providing care to persons with the disease. In addition, social workers are key role players in the interdisciplinary approach to services for older persons and their families. However, social workers need to acquire specialised knowledge and skill in gerontology and dementia care to deal with the demands of an ageing population and the global increase of persons suffering from dementia.

The following chapter focuses on the research methodology and research findings.
CHAPTER 3
RESEARCH METHODOLOGY AND EMPIRICAL RESEARCH FINDINGS

3.1 Introduction

This chapter focuses on the research methodology employed during the research process and the findings that emerged from the interviews on the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga. The data obtained from the interviews with the participants were transcribed and analysed and the research findings presented by means of themes and sub-themes that were identified during data analysis and are supported by both verbatim quotes from interviews and literature.

The goal of the study was:

To explore the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga.

To attain the goal of the research study, the following objectives were pursued:

- To conceptualise Alzheimer's disease as a condition, including incidence, clinical features, etiology, risk factors, diagnosis, treatment and aspects of caregiving from the ecosystems perspective;
- To identify the current support systems available in black rural communities in Mpumalanga to caregivers of persons with Alzheimer’s disease;
- To identify the indigenous beliefs about Alzheimer’s disease in black rural communities in Mpumalanga;
- To explore the challenges faced by caregivers of persons with Alzheimer’s disease in black rural communities in Mpumalanga; and
- To make recommendations for professional support services to caregivers of persons with Alzheimer’s disease in black rural communities in Mpumalanga.
Willig (2008:20) explains that most qualitative research studies are guided by one or more research questions, identifying the phenomenon that the researcher wants to investigate. The research question therefore refers to what the researcher intends to find out or study. In the context of this study, the following research question was asked:

*What are the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga?*

The research question was demarcated into five specific areas, which are the main themes of the study:

- The Alzheimer’s disease caregiver
- Indigenous issues about Alzheimer’s disease
- Caregivers’ understanding of Alzheimer’s disease
- The impact of Alzheimer’s disease on the caregiver
- Support services available in the community for Alzheimer’s disease caregivers

### 3.2 Research approach

The researcher employed the qualitative approach in order to explore and describe the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga.

Qualitative research is a broad umbrella term for research methodologies that were used in this study to explore, describe and explain Alzheimer’s caregiver experiences, behaviours, interactions and social contexts without the use of statistical procedures or quantification (Fossey, Harvey, McDermott & Davidson, 2002:717). This approach can therefore be described as “an inquiry process of understanding” where the researcher develops a complex, holistic picture of Alzheimer’s caregiving, analyses words, reports detailed views of information, and conducts the study in a natural setting (Creswell as quoted by Ivankova et al., 2007:259).
As qualitative research lends itself to developing knowledge in poorly understood or complex areas of health care, the researcher had the opportunity to use unstructured methods to observe and study participants in their natural environment in an effort to understand the phenomena of caregiving within the context of Alzheimer’s disease. Participants had the opportunity to express themselves freely and were not restricted by rigid questions. This assisted the researcher to gather in-depth information about the needs and experiences of Alzheimer’s caregivers and brought the researcher into close contact with lived experiences of the participants (Gilgun & Abrams, 2002:42).

### 3.3 Type of research

Neuman (2005:24) defines applied research as “research designed to offer practical solutions to a concrete problem or address the immediate and specific needs of clinicians or practitioners.” This study can be described as applied research as it focuses on a problem in practice, namely the specific needs and experiences of caregivers of persons with Alzheimer's disease living in black rural communities in Mpumalanga and seeks to generate solutions to the problems. This study expands the knowledge base of social workers and other professionals in the field of gerontology and assists them in their work with caregivers of persons with Alzheimer’s disease.

### 3.4 Research design

The case study design was followed as it enabled the researcher to further his understanding about the social issue at hand (Alzheimer’s disease), and the population being studied (caregivers of persons with Alzheimer's disease in black rural communities in Mpumalanga) (Fouché, 2005:272). Case studies are defined as “a strategy of inquiry in which the researcher explores in depth a program, event, activity, process or one or more individuals” (Stake as quoted by Creswell, 2009:13). When more than one case is studied, it is referred to as a collective case study (Davidson, Worrall & Hickson, 2008:238). The collective case study design furthered the understanding of the researcher about caregiving in the context of Alzheimer’s disease and comparisons could be made between the needs and experiences of the caregivers who participated in the study (Fouché & Schurink, 2011:322).
3.5 Research methods

3.5.1 Population, sample and sampling method

3.5.1.1 Population
A research population is described by Welman, Kruger and Mitchel (2007:52) as the total collection of all units of analysis, of which the researcher wishes to draw specific conclusions. The population in this study consisted of caregivers providing care to persons diagnosed with Alzheimer’s disease in the Ehlanzeni and Nkangala black rural communities ofMpumalanga.

3.5.1.2 Sampling method and technique
Non-probability sampling, and more specifically purposive sampling, was used to meet the specific criteria of the study. Neuman (2005:220) argues that qualitative researchers tend to use non-probability or non-random sampling methods. Willig (2008:17) explains that qualitative research tends to work with relatively small numbers of participants, due to the time-consuming and labour-intensive nature of qualitative data collection and analysis. As described by Rice and Ezzy (in Davidson et al., 2008:238), the selection process was aimed to select cases that would provide comprehensive data to illuminate the study questions. Patton as cited in Davidson et al. (2008:238) suggests that the logic of power of purposive sampling in qualitative research derive from the emphasis on an in-depth understanding of the phenomena investigated. Eight participants were selected from the Ehlanzeni district and three from the Nkangala district ofMpumalanga.

The following selection criteria were applied in selecting the sample:
• Participants had to be caregivers of persons with Alzheimer’s disease within a black rural community for at least one year;
• The persons suffering from Alzheimer’s disease had to be diagnosed with the disease by a medical practitioner;
• The persons suffering from Alzheimer’s disease had to be service recipients of affiliates of Alzheimer’s South Africa or Age-in-Action;
• Participants that are the caregivers had to reside in black rural communities within the Ehlanzeni and Nkangala districts ofMpumalanga;
• Participants had to be aged 18 years and older; and
• Participants had to be a relative, spouse, family member, friend or neighbour of the person suffering from Alzheimer’s disease.

The provincial directors of Alzheimer’s South Africa and Age-in-Action in Mpumalanga provided the researcher with the contact details of caregivers who fit the criteria. The first 11 caregivers whom the researcher contacted, and who met the criteria, were selected. They were invited for an interview where the researcher explained the research study by means of a letter of informed consent. Once they had signed the letter of informed consent, the interviews were conducted.

3.5.1.3 Sample
A sample comprises elements or a subset of the population considered for actual inclusion in the study in an effort to understand the population from which it was drawn (Strydom, 2011:223-224). A sample of 11 caregivers were selected for this study and after the interviews were completed, the researcher was satisfied that saturation has been reached.

3.5.2 Data collection method
Interviewing is the predominant mode of data collection in qualitative research whereby researchers obtain information through direct interchange with an individual that is known, or expected to possess, the knowledge they seek (DePoy & Gilson as cited in Greeff, 2011:342). The aim of qualitative interviews is to see the world through the eyes of the participant and to obtain rich descriptive data, which will help the researcher to understand the participant’s construction of knowledge and social reality (Nieuwenhuis, 2007:87). Face-to-face, semi-structured interviews were used as data collection method for this study. The eleven semi-structured interviews provided the researcher with a detailed picture of the needs and experiences of participants providing care to persons with Alzheimer’s disease. It furthermore provided the researcher with flexibility to follow up particular interesting avenues that emerged during the interviews (Greeff, 2011:351-352). The interviews were conducted in the communities where the participants reside – either at their homes or in community centres nearby – and at a time that suited both the researcher and...
the participants. The researcher made use of translators provided by Alzheimer’s South Africa and Age-in-Action. This was done with the consent of the participants.

An interview schedule was developed to guide the researcher during the interviews, consisting of a set of predetermined open-ended themes and/or questions. Willig (2008:25) cites that the use of an interview schedule during semi-structured interviews allows the researcher to incorporate the participant’s own terms and concepts into the questions, and thus to make the questions more appropriate or relevant to the participant. Themes in the interview schedule focused on the needs and experiences of caregivers providing care to persons with Alzheimer's disease. The themes included the Alzheimer's disease caregiver, indigenous issues about Alzheimer’s disease, caregivers' understanding of Alzheimer's disease, the impact of Alzheimer's disease on the caregiver and support services in the community. Each theme was further divided into a number of sub-themes. Interviews were recorded with an electronic voice recorder with the permission of the participants and were transcribed afterwards. The recordings and transcriptions will be kept in storage at the University of Pretoria, Department of Social Work and Criminology, for a period of 15 years.

3.5.3 Methods of data analysis

In data analysis, the researcher carefully examines empirical information to reach a conclusion based on reasoning and simplifying the complexity in the data (Neuman, 2005:458). Coding is the process of organising the material into segments of text, before bringing meaning to the data (Creswell, 2009:186). The data collected from the semi-structured interviews were transcribed and coded and themes were generated after reading and rereading the transcriptions a few times.
3.5.3.1 Steps in data analysis

For the purpose of this study, the following linear steps proposed by Creswell, Marshall and Rossman, as described by Schurink, Fouché and De Vos (2011:404-419), were applied:

- **Planning for recording of data**
  The researcher planned for the recording of the data in a systematic manner, which was appropriate to the setting, participants, or both, and which facilitated the analysis before data collection commenced. The researcher made use of tape recordings and ensured that all equipment was in good working order, prior to data collection. This was done with the knowledge and consent of the participants. All interviews were conducted in locations that were conducive to both the researcher and participants. The services of a translator were used to assist the researcher during the interviews. Field notes were used to compliment tape recordings. The researcher furthermore implemented a system to ease data retrieval for analysis. Notes were colour coded to keep track of dates, names, and other valuable information.

- **Data collection and preliminary analyses**
  The data was analysed as soon as it were gathered in order to generate “rich” data. This allowed for revision in data collection strategies and procedures, as well as for obtaining more information from participants where needed.

- **Managing the data**
  During this early stage, the researcher organised the data gathered on index cards and file folders. The researcher then converted the files to appropriate text units, e.g. words, a sentence, or an entire story for analysis by hand. The researcher developed an inventory to control the data gathered, as well as any outstanding data. During this step, the researcher started to transcribe interviews and organised and typed up handwritten field notes. Backup copies of all data were made and stored in a secure place. Various copies of the transcriptions and field notes were made to work on.
• **Reading and writing memos**
During this step in the data analysis process, the researcher read the transcripts in their entirety several times, seeking to get a sense of the interview as a whole, before breaking it into parts, and to become familiar with the data. The researcher initiated the coding process by reading the data repeatedly, identifying patterns and categories. The researcher wrote memos, including key concepts and ideas, in the margins of field notes and transcripts during this initial process of exploring the database.

• **Generating categories and coding the data**
This step in the data analysis process demanded from the researcher a heightened awareness of the data, a focused attention to the data, and openness to the subtle, tactic undercurrents of social life. The researcher noted regularities in the data and identified categories, themes, or dimensions of information. The themes were divided into sub-themes in an effort to reduce the data into small, manageable sets. During this step, data was coded, generating categories and themes. Abbreviations and colours were used to code data.

• **Testing emergent understandings and searching for alternative explanations**
During this step, the researcher began the process of evaluating the data for their usefulness and centrality to the phenomenon being studied. The researcher further evaluated and explored his understanding of the data and challenged his own understanding thereof.

It is of importance to the researcher to challenge apparent patterns in the data during this stage of the data analysis process. The researcher searched for other explanations of these data and the linkages between them that would demonstrate why the explanation offered is the most plausible.

• **Presenting the data**
The final phase of data analysis entailed the presentation of the information by the researcher in written form. This interpretation was done by means of visual images of the information, tables and figures, and was presented in the form of verbatim
quotes from the interviews to support the themes and sub-themes, which were substantiated with literature.

### 3.5.4 Trustworthiness of data

Qualitative research seeks to understand the subject being investigated and provide explanations of the behaviours and experiences of individuals or groups. However, Whiting and Sines (2012:22) argue that one of the major challenges in qualitative research is establishing confidence and trust in the theoretical insights that the researcher proposes to explain or understand the phenomenon being studied.

To ensure reliability in qualitative research, examination of trustworthiness is imperative (Seale in Golafshani, 2003:601). Research findings should be as trustworthy as possible and every research study must be evaluated in relation to the procedures used to generate the findings. In qualitative research, the concepts of credibility, transferability, dependability and conformability are used to describe various aspects of trustworthiness or the “truth value” of the research study (Graneheim & Lundman, 2004:109; Schurink et al., 2011:419-422). Trustworthiness can be established when findings reflect the meanings described by the participants as closely as possible (Lincoln & Guba in Lietz, Langer & Furman, 2006:444).

**Credibility** deals with the focus of the research and refers to the confidence in how well data and processes of analysis address the intended focus (Graneheim & Lundman, 2004:109). Morrow (2005:252) refers to credibility as “internal consistency” in qualitative research. Credibility was achieved by prolonged engagement with participants; persistent observation in the field; researcher reflexivity; and participant checks or validation.

**Transferability** refers to whether the findings of the research study can be transferred from a specific situation or context to another (Graneheim & Lundman, 2004:109). Transferability was ensured by consulting and comparing the findings of similar studies done in different contexts. In addition, as suggested by Morrow (2005:252), the researcher provided sufficient information about the self (the researcher as instrument) and the research context, processes, participants, and
researcher-participant relationships to enable the reader to determine the transferability of the research findings.

**Dependability** relates to whether the research process is logical, well documented and audited (Graneheim & Lundman, 2004:109). Morrow (2005:252) asserts that the way in which a study is conducted should be consistent across time, researchers, and analysis techniques. Dependability was accomplished through carefully tracking the emerging research design and through keeping an audit trail, that is, a detailed chronology of research activities and processes; influences on the data collection and analysis; emerging themes, categories, or models; and analytic memos.

The last aspect, **conformability**, relates to the objectivity of the study and whether the findings of the study could be confirmed by another (De Vos, 2005:346; Schurink et al., 2011:420-421). Gasson in Morrow (2005:252) emphasises that “findings should represent, as far as is (humanly) possible, the situation being researched rather than the beliefs, or biases of the researcher.” From the representation of data, descriptions were made and conclusions were drawn. The researcher completed a detailed literature review in order not to evaluate himself, but to rely solely on the data and then to substantiate it with the literature. Also, the researcher efficiently tied together the data, analytic processes, and findings in such a way that the reader is able to confirm the adequacy of the findings.

Where possible, research findings were substantiated by literature. In addition, the researcher consulted with other professionals in the field of dementia care in order to evaluate the research findings and therefore ensure trustworthiness of data (Lincoln & Guba in Lietz et al., 2006:444).

**3.6 Pilot study**

Strydom and Delport (2011:394) emphasise the importance of conducting a pilot study. The purpose of the pilot study is to determine certain trends, and whether the relevant data can be obtained from the participants. The pilot study can therefore be viewed as a “dress rehearsal” of the main study. Janesick as cited in Strydom and
Delport (2011:395) states that the pilot study in qualitative research allows the researcher to test certain questions and to focus on specific areas that had been unclear. This will afford the researcher the opportunity to refine the interviewing prior to the main investigation. The pilot study will further assist in estimating the time and costs involved, as well as in pre-empting the problems that may arise during the actual qualitative interviews. Two participants were sampled in the same way as the main study to participate in the pilot study. The pilot study tested the interview schedule to ensure that the questions and/or themes generate appropriate responses from the participants. Corrections were made to the interview schedule, interview venues, and settings on the voice recorder, time taken to conduct interviews and the interview process as relevant issues that arose from the pilot testing. This data was not used in the main study.

3.7 Ethical issues

The researcher had a moral and professional obligation to conduct the study in an ethical manner. Willig (2008:19) argues that the human interaction in qualitative inquiries affects researchers and participants, and the knowledge produced through qualitative research affects our understanding of the human condition. The same author further accentuates that researchers should protect their participants from any harm or loss and maintain their psychological wellbeing and dignity at all times. From this point of view, ethical issues arise from the very beginning of the research. Creswell (2009:87) emphasises that researchers need to anticipate and address the ethical issues that may arise during their studies. Strydom (2011:114) defines ethics as “a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.”
The following ethical issues were taken into consideration during the research study:

3.7.1 Informed consent
Royse as quoted by Strydom (2011:117) explains that “obtaining informed consent implies that all possible or adequate information on the goal of investigation, the procedures that will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, be rendered to potential subjects or their legal representatives.” Neuman (2005:135) describes informed consent as “a statement, usually written, that explains aspects of a study to participants and asks for their voluntary agreement to participate before the study begins.” A letter of informed consent was compiled by the researcher, which included an overview of the purpose and procedures of the study, including the use of a voice recorder. The letter was signed by the participants voluntarily in order to include them in the research study.

3.7.2 Protection from harm
Research should never cause harm to the people being studied, regardless whether they volunteer for the study (Babbie, 2007:63). Strydom (2011:115) distinguishes between physical and emotional harm, and argues that harm to participants in the social sciences will be mainly of an emotional nature.

As emotional harm may often hold far-reaching consequences for participants, harm to the participant was minimized as far as possible. The researcher was honest, respectful and sympathetic towards all participants. The researcher debriefed all participants after the interviews. Although provision was made, it was not necessary to refer any of the participants for counselling after the interviews.

3.7.3 Privacy, confidentiality and anonymity
Privacy, confidentiality and anonymity in the study conducted were regarded as crucial as it was anticipated that participants would share their personal feelings, experiences and observations. Grobler, Du Toit and Schenck (2003:110) cite that confidentiality refers to what has been said will remain within the relationship and that it will not be repeated to someone else. Strydom (2011:119) defines privacy as “to keep to oneself that which is normally not intended for others to observe or analyse.”
All participants’ information and responses shared during the study were kept confidential, and the results were presented in an anonymous manner to protect the identities of the participants, by using pseudonyms or numbers. Under no circumstances was the identity of the participants made known to any other party.

3.7.4 Deception of participants
Corey as quoted by Strydom (2011:119) points out that deception involves withholding information, or offering incorrect information in order to ensure the participation of subjects when they would otherwise possibly have refused it. The researcher was honest, transparent and truthful towards participants during the course of the study. Prior to the conducted interviews, participants were provided with a description of the study and its purpose, benefits of participation, the risks involved, and what their involvement level would be if they chose to continue with the interview. Participants were provided with the opportunity to ask questions to the researcher to clarify any misunderstandings.

3.7.5 Debriefing of participants
Babbie (2007:67) asserts that debriefing entails interviews to discover any problems or misunderstanding generated by the research experience, so that those problems can be corrected. Debriefing sessions provide participants with the opportunity, after the study, to work through their experience and its aftermath, and to assist participants to minimize possible harm (Strydom, 2011:122). The researcher conducted debriefing interviews with all participants after the study.

3.7.6 Actions and competence of the researcher
Strydom (2011:123) accentuates that researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake a proposed study. The researcher is deemed competent to conduct this study as he is registered as a social worker with the South African Council for Social Service Professions and has successfully completed the theoretical module in research methodology for the MSW (Health Care) degree at the University of Pretoria. The study was furthermore conducted under the guidance and supervision of a senior lecturer of the Department of Social Work and Criminology, University of Pretoria.
3.7.7 Release or publication of the findings
Strydom (2011:126) emphasises that the findings of a research study must be introduced to the reading public in written form; otherwise even a highly scientific investigation will mean very little and will not be viewed as research. The findings of this study were published in the form of a mini-dissertation in accordance with the requirements of the University of Pretoria. The research report was compiled as accurately and objectively as possible, and contained all essential information. The findings of the research will furthermore be shared with all stakeholders involved.

In addition to the ethical aspects discussed in section 3.7.1 to 3.7.7, the researcher conducted the research according to the ethics and research guidelines of the University of Pretoria.

3.8 Research findings

This section is a presentation of the data that was collected during the research process. The data is presented in the form of a profile of the participants and a thematic analysis of the themes generated from the research.

3.8.1 Biographic profile of participants
The biographic information of the participants is described in Table 3.1 below.
### Table 3.1: Biographic profile of participants

<table>
<thead>
<tr>
<th>PARTICIPANT NUMBER AND DISTRICT OF MPUMALANGA</th>
<th>GENDER AND RACE</th>
<th>AGE</th>
<th>RELATIONSHIP STATUS</th>
<th>RELATION TO ALZHEIMER’S PERSON</th>
<th>PERIOD OF CAREGIVING</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Ehlanzeni</td>
<td>Male Black</td>
<td>82</td>
<td>Married</td>
<td>Spouse</td>
<td>8 years</td>
</tr>
<tr>
<td>2 Ehlanzeni</td>
<td>Female Black</td>
<td>68</td>
<td>Married</td>
<td>Daughter</td>
<td>3 years</td>
</tr>
<tr>
<td>3 Ehlanzeni</td>
<td>Female Black</td>
<td>46</td>
<td>Single</td>
<td>Daughter</td>
<td>11 years</td>
</tr>
<tr>
<td>4 Ehlanzeni</td>
<td>Female Black</td>
<td>54</td>
<td>Widow</td>
<td>Sister-in-law</td>
<td>15 years</td>
</tr>
<tr>
<td>5 Ehlanzeni</td>
<td>Female Black</td>
<td>47</td>
<td>Married</td>
<td>Sister-in-law</td>
<td>11 years</td>
</tr>
<tr>
<td>6 Ehlanzeni</td>
<td>Female Black</td>
<td>70</td>
<td>Single</td>
<td>Maternal aunt</td>
<td>6 years</td>
</tr>
<tr>
<td>7 Ehlanzeni</td>
<td>Female Black</td>
<td>44</td>
<td>Married</td>
<td>Daughter-in-law</td>
<td>4 years</td>
</tr>
<tr>
<td>8 Ehlanzeni</td>
<td>Female Black</td>
<td>23</td>
<td>Single</td>
<td>Granddaughter</td>
<td>2 years</td>
</tr>
<tr>
<td>9 Nkangala</td>
<td>Female Black</td>
<td>63</td>
<td>Married</td>
<td>Spouse</td>
<td>1 year</td>
</tr>
<tr>
<td>10 Nkangala</td>
<td>Female Black</td>
<td>48</td>
<td>Single</td>
<td>Daughter</td>
<td>15 years</td>
</tr>
<tr>
<td>11 Nkangala</td>
<td>Female Black</td>
<td>61</td>
<td>Living with partner</td>
<td>Stepdaughter</td>
<td>5 years</td>
</tr>
</tbody>
</table>

Eight of the participants were residing in rural communities in the Ehlanzeni district of Mpumalanga, whilst three of the participants were residing in the Nkangala district of Mpumalanga. One participant was male and ten were female. The age of the participants ranged from 23 to 82 years with the mean age being 55.09 years. Five of the participants were married, four were single, one widowed and one participant was living with her partner. All the participants were related (family members) to the persons with Alzheimer’s disease to whom they were providing care. The period of providing care to a person with Alzheimer’s disease ranged from one to 15 years.
with the mean period being 7.36 years. The profile of the participants will be further discussed in section 3.8.1.1. Table 3.2 provides a profile of the research participants:

**Table 3.2: Profile of research participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>A married black male of 82 years. His wife and he live in a house in a rural community in the Ehlanzeni district of Mpumalanga. His wife is 82 years old and was diagnosed with Alzheimer’s disease in 2006. He looks after her. The participant was born in Malawi and did not attend school. The couple has three children, who are all deceased. He also takes care of the daughter of a relative, who passed away. She is 12 years old. The participant and his wife both receive old age grants. The participant attends the local mosque. Home-based care services visit the participant and his wife on a weekly basis. The participant and his wife make use of state health care services.</td>
</tr>
<tr>
<td>Participant 2</td>
<td>A married female of 68 years. She completed grade 2 at school. She and her family live in a rural village in the Ehlanzeni district of Mpumalanga. The participant has looked after her mother of 94 years, since she was diagnosed with Alzheimer’s disease three years ago. Her mother attends a local service centre from Mondays to Fridays. She is also looking after her three grandchildren, although their parents are still alive. The participant attends the services of the Zion Christian Church three times per week. The participant and her mother receive old age grants. The person with Alzheimer’s disease has four other children. They do not live in the same community as their mother. The person with Alzheimer’s disease makes use of state health care services should the need arise. The local home-based care services visit the family on a regular basis.</td>
</tr>
<tr>
<td>Participant 3</td>
<td>A 46-year-old female who looks after her 86-year-old father who was diagnosed with Alzheimer’s disease in 2003. They live in a rural village in the Ehlanzeni district of Mpumalanga. The participant never attended school. She is not married and receives a disability grant, as she suffered a stroke some years ago. The participant has five children of which one lives with her. The person with Alzheimer’s disease receives an old age grant. The participant is a member of the Twelve Apostles Church and attends services every afternoon and on Sundays. She received caregiver training from Alzheimer’s South Africa. The participant and her father make use of state health care services. She and her father are members of the local service centre. The participant attends Alzheimer’s support group meetings at the service centre once per month. She does not receive any support from home-based care services.</td>
</tr>
<tr>
<td>Participant 4</td>
<td>Participant 4 is a 54-year-old female who resides in a rural village in the Ehlanzeni district of Mpumalanga. She is a widow and takes care of her brother-in-law of 62 years who was diagnosed with Alzheimer’s disease in 1990. The person with Alzheimer’s disease has only one child who disappeared some years ago. The participant has six children of whom five are alive. The children live with her and one suffers from epilepsy. The participant receives a private pension from her late husband’s employer. Her brother-in-law receives an old age grant. The participant is a member of the Whistle Church and attends services every Tuesday and Sunday. Both the participant and the person with Alzheimer’s disease make use of state health care services. They are not supported by home-based care services.</td>
</tr>
<tr>
<td>Participant 5</td>
<td>Participant 5 is a 47-year-old female living in a rural village in the Ehlanzeni district of Mpumalanga. She attended secondary school and passed grade 11. The participant is married and has four children of which two lives with her. She also looks after 10 orphaned children who live with her. The participant looks after her 61-year-old brother-in-law who was diagnosed with Alzheimer’s disease in 2006. Her husband is his only family member. She is a member of the Christian Fire Church and attends services on Fridays and Sundays. The participant does not receive any government grant. Her brother-in-law has recently applied for an old age grant. The participant received caregiver training from Alzheimer’s South Africa during 2011. The participant and the person with Alzheimer’s disease make use of state medical services. The person with the disease sometimes attend the local service centre, but not on a regular basis. The participant and the person with Alzheimer’s disease do not receive any support from home-based care services.</td>
</tr>
<tr>
<td>Participant 6</td>
<td>Participant 6 is a female of 70 years. She never married and never attended school. She lives in a rural village in the Ehlanzeni district of Mpumalanga. She looks after her sister’s son who is 55 years of age and who was diagnosed with Alzheimer’s disease six years ago. The participant had nine children of which only one is alive. She is also looking after her seven grandchildren, as their parents are deceased. She receives an old age grant as well as a child support grant in respect of the children in her care. Her sister’s son receives a disability grant. The participant is a member of the Roman Catholic Church and attends church services on Sundays. She and her sister’s son make use of state health care services. Both participant and the person with Alzheimer’s disease attend the local service centre. They do not receive any support from home-based care services.</td>
</tr>
<tr>
<td>Participant 7</td>
<td>Participant 7 is a 44-year-old female who looks after her mother-in-law who was diagnosed with Alzheimer’s disease five years ago. She is married with six children. Her husband works and lives in Swaziland. All the children live in the house. The participant attended secondary school and passed grade 10. She resides in a rural village in the Ehlanzeni district of Mpumalanga and receives a child support grant. The person with Alzheimer's disease is 70 years old and receives an old age grant. The participant belongs to the Emmanuel Assembly Church and attends church services on Mondays, Wednesdays and Sundays. The person with Alzheimer's disease has a brother and eight children of which six are alive. Both the person with Alzheimer's disease and the participant makes use of state health care services. Home-based care services visit the family once per week.</td>
</tr>
<tr>
<td>Participant 8</td>
<td>Participant 8 is a young woman of 23, who lives in a rural community in the Ehlanzeni district of Mpumalanga. She is not married and looks after her grandfather of 60 since he was diagnosed with Alzheimer's disease two years ago. The participant attended secondary school and passed grade 11. She has two children who live with her. The person with Alzheimer's disease has three children of whom one lives in Gauteng. The participant receives a child support grant and her grandfather an old age grant. She does not attend church. The participant and her grandfather make use of state health care services. She is HIV positive and receives anti-retroviral treatment. The participant and the person with Alzheimer’s disease do not receive any support from home-based care services.</td>
</tr>
<tr>
<td>Participant 9</td>
<td>Participant 9 is a 63-year-old female who lives in a rural community in the Nkangala district of Mpumalanga. She looks after her 70-year-old husband who was diagnosed with Alzheimer’s disease 18 months ago. They have been married for 26 years and have one child. The participant passed grade 8. She and her husband receive old age grants. Her husband has a cousin who lives in Middelburg. All other family members are deceased. The participant attends church every Sunday. Home-based care services visit the family three times per week. Both the participant and her husband make use of state health care services.</td>
</tr>
<tr>
<td>Participant 10</td>
<td>Participant 10 is a 48-year-old female who resides in a rural setting in the Nkangala district of Mpumalanga. She looks after her 84-year-old mother who was diagnosed with Alzheimer’s disease. Since 1999, when she was diagnosed with Alzheimer’s disease. She receives a child support grant and her mother an old age grant. The participant is a member of the St</td>
</tr>
</tbody>
</table>
Paul’s Church and regularly attends church services. The person with Alzheimer’s disease has three sisters who live in Hendrina. The family does not receive support from home-based care services and makes use of state health care services.

Participant 11 is a female of 61 years. She is not married, but lives with her partner in a rural community in the Nkangala district of Mpumalanga. The participant did not attend school. She looks after her stepfather for the past five years. He was diagnosed with Alzheimer’s disease three years ago. The participant has two children. Her three grandchildren live with her. She does not receive any government grant. The person with Alzheimer’s disease is 70 years old. He has a sister that lives in Emalahleni and receives an old age grant. The participant is a member of the Apostolic Church of Zion and attends church services. The participant suffers from TB and is HIV positive. She receives antiretroviral treatment. The participant and her stepfather are making use of state health care services. She attends Alzheimer’s support groups three times per month. The person with Alzheimer’s disease attends the local service centre from Mondays to Fridays. Home-based care services support the family.

3.8.1.1 The Alzheimer’s caregiver
This section focuses on the Alzheimer’s caregiver, including the period of caregiving, relationship with the person with Alzheimer’s disease, age, gender and level of education of the caregiver.

- **Period of caregiving**
The period of providing care to a person with Alzheimer’s disease ranged from one to 15 years with the average period of caregiving being 7.36 years. Sixty-four percent of the caregivers have been providing care for a period of 5 years and longer and 36 percent for a period exceeding 10 years.

In a study conducted by Juozapavicius and Weber (2001:14), findings showed that 60 percent of caregivers provided care to persons with Alzheimer’s disease for a period exceeding five years, whilst 35 percent provided care for a period of 6 to 10 years. The same study found that only 5 percent of caregivers provided care for less than one year whilst 25 percent of caregivers provided care for a period of 11 to 15 years. In another study, Castro et al. (2007:94) found the average duration of caregiving to be 5.02 years.
• **Relationship with the person with Alzheimer’s disease**

All the participants had a familial relationship with the Alzheimer’s disease sufferer. Two of the participants were spouses (18%), six were daughters, i.e. own daughters, stepdaughters or daughters-in-law (55%), one was a maternal aunt (9%) and two were sisters-in-law (18%).

Literature indicates that, in South Africa, family members are the primary caregivers to elderly relatives with dementia (Kalula & Petros, 2011:33). A study conducted by Kalula et al. (2010:450), in the urban setting of Cape Town, revealed that family members cared for 79 percent of persons with dementia.

• **Age of caregiver**

The age of the participants ranged from 23 to 82 years with the average age being 55 years. Three of the participants (27%) were older than 65 years. Only one participant (9%) was younger than 25 years. In a recent study conducted in the United States of America, it was found that 23 percent of caregivers of persons with Alzheimer’s disease and other dementias were 65 years of age or older (Alzheimer’s Association, 2013:221). In another study, Juozapavicius and Weber (2001:14) found that 40 percent of Alzheimer caregivers were 65 years of age and older. Very often these caregivers are themselves older persons with one or more chronic health conditions (Bauer et al., 2001:329).

• **Gender of caregiver**

Ten of the participants (91%) were female and only one (9%) was male. Bauer et al. (2001:329) cite that women provide the majority of care for dependent older persons. In addition, Bartfay and Bartfay (2013:99) explain that in many countries around the world, providing care to a family member often falls on the shoulders of women, including daughters and/or elderly spouses.
• **Level of caregiver educational attainment**

Table 3.3 shows the level of education of the participants. The level of educational attainment is indicated in highest school grade passed.

**Table 3.3: Level of educational attainment of participants**

<table>
<thead>
<tr>
<th>PARTICIPANT</th>
<th>LEVEL OF EDUCATIONAL ATTAINMENT IN SCHOOL GRADES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>None</td>
</tr>
<tr>
<td>2</td>
<td>Grade 2</td>
</tr>
<tr>
<td>3</td>
<td>None</td>
</tr>
<tr>
<td>4</td>
<td>Grade 7</td>
</tr>
<tr>
<td>5</td>
<td>Grade 11</td>
</tr>
<tr>
<td>6</td>
<td>None</td>
</tr>
<tr>
<td>7</td>
<td>Grade 10</td>
</tr>
<tr>
<td>8</td>
<td>Grade 11</td>
</tr>
<tr>
<td>9</td>
<td>Grade 8</td>
</tr>
<tr>
<td>10</td>
<td>Grade 5</td>
</tr>
<tr>
<td>11</td>
<td>None</td>
</tr>
</tbody>
</table>

Four of the participants did not attend school. Four participants attended secondary school although none of them have completed grade 12. Three participants attended primary school only. However, only one of those who attended primary school completed grade 7.

A study led by Castro et al. (2007:93), found that 60 percent of American rural caregivers had at least a high school degree or equivalent. Twenty-five percent had less than a high school education, and 15 percent had a college degree or greater.

The majority of participants thus had a limited level of educational attainment. Marks et al. (2008:363) assert that these caregivers would experience more problematic wellbeing effects than caregivers with more education. Lahaie et al. (2012:248)
highlight the need for more research to examine the relationship among caregivers’ educational attainment, the extent of their caregiving and its impact on their own wellbeing. The ecosystems perspective shows the interrelatedness between educational attainment and caregiver wellbeing.

### 3.8.2 Themes and sub-themes
Research findings are discussed according to the themes and sub-themes that were identified, and the thematic analysis thereof. Verbatim quotes from the research interviews are used to support these themes. The themes are further substantiated with literature from chapter two. Table 3.4 provides an overview of the themes and sub-themes generated from the research.

*Table 3.4: Themes and sub-themes of research*

<table>
<thead>
<tr>
<th>THEMES</th>
<th>SUB-THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Alzheimer’s disease caregiver</td>
<td>• Caregiver remuneration</td>
</tr>
<tr>
<td></td>
<td>• Hours per day and week providing care</td>
</tr>
<tr>
<td></td>
<td>• Caregiving tasks</td>
</tr>
<tr>
<td></td>
<td>• Caregiver training</td>
</tr>
<tr>
<td>Indigenous issues about Alzheimer’s disease</td>
<td>• Community knowledge of Alzheimer’s disease and attitudes</td>
</tr>
<tr>
<td></td>
<td>• Indigenous beliefs</td>
</tr>
<tr>
<td></td>
<td>• Traditional treatment practices</td>
</tr>
<tr>
<td>Caregivers’ understanding of Alzheimer’s disease</td>
<td>• Alzheimer’s disease as a medical condition</td>
</tr>
<tr>
<td></td>
<td>• Causes</td>
</tr>
<tr>
<td></td>
<td>• Symptoms</td>
</tr>
<tr>
<td></td>
<td>• Medical treatment and prognosis</td>
</tr>
<tr>
<td>The impact of caregiving</td>
<td>• Physical impact</td>
</tr>
<tr>
<td></td>
<td>• Psychological impact</td>
</tr>
<tr>
<td></td>
<td>• Social impact</td>
</tr>
<tr>
<td></td>
<td>• Positive aspects of caregiving</td>
</tr>
</tbody>
</table>
### Support services in the community

<table>
<thead>
<tr>
<th>THEMES</th>
<th>SUB-THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUPPORT SERVICES IN THE COMMUNITY</td>
<td>• Health care services</td>
</tr>
<tr>
<td></td>
<td>• Home-based care services</td>
</tr>
<tr>
<td></td>
<td>• Respite care</td>
</tr>
<tr>
<td></td>
<td>• Social work services</td>
</tr>
<tr>
<td></td>
<td>• Support groups</td>
</tr>
<tr>
<td></td>
<td>• Institutional care</td>
</tr>
<tr>
<td></td>
<td>• Religious institutions</td>
</tr>
</tbody>
</table>

#### 3.8.2.1 Theme 1: The Alzheimer’s caregiver

This section focuses on the Alzheimer’s caregiver, including caregiver remuneration, hours per day and week providing care, caregiving tasks provided and caregiver training received.

- **Sub-theme 1.1: Caregiver remuneration**

  None of the participants reported that they receive any remuneration for providing care to persons with Alzheimer’s disease. They stated the following:

  “I don’t get paid to look after my mother. My family expects of me as her daughter to look after her.”

  “No, I am not paid. It is my duty to look after my husband. He has always been good to me.”

  “In our culture, we look after our older family members.”

This finding correlates with the sentiments of Llanque and Enriquez (2012:23) that black caregivers are typically unpaid females, and Lahaie et al. (2012:245) which state that women provide the majority of unpaid care to older persons. In 2013, unpaid caregivers provided an estimated 17.7 billion hours of informal care to persons with dementia in the United States of America. The value of this contribution is valued at over $220.2 billion (Alzheimer’s Association, 2014:30).
Most participants reported that they receive government grants, e.g. old age pensions, disability grants and/or child support grants. Two participants indicated that they have no income. This finding is in contrast with a study conducted by Castro et al. (2007:93) among rural caregivers in the United States of America where the median income was approximately $20 000 to $25 000 annually. It can therefore be said that the majority of rural Alzheimer’s caregivers live in poverty that, from an ecosystems perspective, can have a negative impact on their own wellbeing and their ability to provide care to the person with the disease. Although the study found that rural caregivers provide unpaid care to persons with Alzheimer’s disease, the caregivers reported that they were motivated by a sense of culture and family responsibility to look after their loved ones with the disease.

- **Sub-theme 1.2: Hours per day and week providing care**
  The participants had difficulties to specify the exact hours of care that they provide to their relatives with Alzheimer’s disease. However, most participants indicated that they provide care 24 hours per day and seven days per week. The participants explained as follows:

  “I am the one that does all the cooking, washing and cleaning and when he is not in the house I have to look for him.”

  “I am looking after him 24 hours per day and seven days per week as I am bathing him, feeds him and watches him.”

  “I always look after her because if I don’t look after her, she goes out of the gate. Even at night.”

Two participants reported that their relatives with Alzheimer’s disease are attending service centres (luncheon clubs) during the day and therefore they only provide care during night times and weekends. One participant explained that she only provides care at night as other family members assist her during the day. In terms of the ecosystems perspective, the lack of opportunities in the community, such as social support, can have a negative effect on the functioning of individuals.
Literature reports inconsistent findings concerning the average time spent on caregiving tasks. Alzheimer’s Association (2014:30) indicates an average of 16 to 30 hours per week, whilst Davis et al. (in McCarron et al., 2002:265) report an average of 11 hours over a 24-hour period. The findings show that caregivers in rural communities provide care to persons suffering from Alzheimer’s disease for extended hours per day without significant relief offered by other persons or community structures.

- **Subtheme 1.3: Caregiving tasks**

Alzheimer’s caregiving tasks are linked to deterioration in cognition, function and behaviour throughout the various stages of the disease (Alzheimer’s Association, 2011:220; Alzheimer’s Disease International, 2013:25). Table 2.6 in section 2.7.1 summarises characteristic features of Alzheimer’s disease and associated caregiving tasks during disease progression.

Table 3.5 provides a comparison of the caregiving tasks described by Alzheimer’s Association (2011:220) and Alzheimer’s Disease International (2013:25) and the involvement of participants in the specified caregiving tasks.

*Table 3.5: Caregiving tasks provided by participants compared with caregiving tasks indicated in literature*

<table>
<thead>
<tr>
<th>STAGE</th>
<th>CAREGIVING TASKS DESCRIBED IN LITERATURE</th>
<th>PERCENTAGE OF PARTICIPANTS INVOLVED IN IDENTIFIED CAREGIVING TASKS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early stages</td>
<td>• Provide emotional support</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>• Remind person about events and tasks</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>• Provide assistance with instrumental activities such as managing finances, household chores and shopping</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>• Help with taking medication and following</td>
<td>64%</td>
</tr>
</tbody>
</table>
### Treatment Recommendations

<table>
<thead>
<tr>
<th>Middle stage</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Increased and constant supervision</td>
<td>100%</td>
</tr>
<tr>
<td>• Assistance with communication strategies</td>
<td>55%</td>
</tr>
<tr>
<td>• Help with personal care and hygiene</td>
<td>100%</td>
</tr>
<tr>
<td>• Help with transportation</td>
<td>100%</td>
</tr>
<tr>
<td>• Increased help with activities of daily living such as food preparation,</td>
<td>100%</td>
</tr>
<tr>
<td>feeding, appropriate dressing, bathing and toileting</td>
<td></td>
</tr>
<tr>
<td>• Supervise person to avoid unsafe activities such as wondering and getting</td>
<td>91%</td>
</tr>
<tr>
<td>lost</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Final stages</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Care, support and supervision are constant</td>
<td>100%</td>
</tr>
<tr>
<td>• Full physical care has to be provided</td>
<td>100%</td>
</tr>
<tr>
<td>• Deal with behavioural problems</td>
<td>64%</td>
</tr>
</tbody>
</table>

The caregiving tasks indicated by the participants correlate with the caregiving tasks described in literature. It is evident that the intensity of the caregiving tasks increases as Alzheimer's disease progresses to its final stages where the person suffering from the disease needs support and assistance with all activities of daily living.

- **Sub-theme 1.4: Caregiver training**

Only two participants reported that they have received training for providing care to persons with Alzheimer's disease. The training was provided by Alzheimer's South Africa. The other participants indicated that such training would assist them to provide better care to their relatives with the disease. The participants explained:

"Training will help me to become a better caregiver to my husband. I just do what I think is right for him."

"I don't know a lot about the disease. Maybe training will help me to understand it better."
I think training will help me to cope with my situation.“

Kwok et al. (2011:288) report that caregivers often lack the knowledge to carry out proper caregiving and are therefore overwhelmed by the immense caregiving demands. Literature shows that skills training could improve the quality of life in caregivers (Vellone et al., 2012:48), alleviate some of the potential stress placed on them (Scharf, Bell & Smith, 2006:560) and produce positive caregiving outcomes (Gallagher-Thompson & Coon in Villareal-Reyna et al., 2012:974-975).

The findings of the study indicate that rural caregivers are often unskilled to provide in the caregiving needs of their family members with Alzheimer’s disease. Skills training, in terms of the theoretical framework, can build on the existing strengths of caregivers, achieve positive changes in their psychosocial functioning and provide opportunities for more satisfying living.

- Discussion of theme 1
None of the participants indicated that they receive any remuneration for their caregiving responsibilities. Instead, they reported a sense of duty as well as family and cultural expectations to provide care to their family members with Alzheimer’s disease. Most participants mentioned government grants as their only source of income. The vast majority of participants reported that they provide care for extended hours. A range of caregiving tasks were reported by the participants, including most activities of daily living. Only two participants received caregiving training. Nevertheless, all participants agreed that such training would be beneficial. The ecosystems perspective posits that human wellbeing is influenced by various factors and at various levels, such as the socioeconomic and cultural environment in which individuals find themselves.

3.8.2.2 Theme 2: Indigenous issues about Alzheimer's disease
This theme focuses on the indigenous issues about Alzheimer’s disease and is divided into three sub-themes. The sub-themes explore community knowledge and attitudes, cultural perspectives and indigenous beliefs that may influence the caregiving experience and traditional treatment practices related to Alzheimer’s disease.
• Sub-theme 2.1: Community knowledge of Alzheimer’s disease and attitudes

Some studies conducted in Africa have suggested that the experience of stigma by people with mental illness may be common, but there is no information on how widespread negative attitudes to mental illness may be in the community (Gureje, Lasebikan, Ephraim-Oluwanuga, Olley & Kola, 2005:436). However, Gureje (2007:12) is of the opinion that mentally ill persons in Africa, such as persons suffering from Alzheimer’s disease, are commonly socially alienated and often abused because of their illness. Moreover, it was found that stigma might cause increased burden for family members (Werner & Heinik, 2008:92). An older study by MacRae (1999:58) found that only 30 percent of spousal caregivers and 29 percent of child caregivers did not appear to have experienced stigma.

People have varying knowledge about Alzheimer’s disease. Edwards et al. (2000:27) explain that misconceptions and ignorance about Alzheimer’s disease negatively affect caregivers and the victims themselves. Vellone et al. (2012:52) point out that caregivers often feel isolated and abandoned, because of the communities’ lack of knowledge about Alzheimer’s disease.

The participants experienced the knowledge and attitude of the community towards Alzheimer’s disease and the Alzheimer’s sufferer in different ways. The participants used the following phrases to explain their perceptions and experiences:

“It is only the neighbours who understand goggo’s (old lady with Alzheimer’s disease) condition, but the others, far from here, don’t know. The people from around here understand. If she goes across the road, then they say she is a witch because they don’t understand.”

“They just look at her and nobody cares.”

“The community must also be taught about this thing (Alzheimer’s disease) so that they will understand what is happening. They need awareness.”
“Yes, they (the community) understand because sometimes, when he is in the road, they will remove him from the street and call me. When he is sick, they do come and support me when I need help.”

“The people who don’t hear about Alzheimer’s disease really don’t understand this disease.”

“My neighbours understand after I talked to them about it.”

“The community understands the disease. Just the other day I went to bath her and goggo (old lady with Alzheimer’s disease) just quickly got out and they phoned me and said she was here.”

“I don’t really think that they understand the disease.”

The findings of the study suggest that participants experienced the understanding and attitude of the community about Alzheimer’s disease in different ways. It seems as if neighbours, living in close proximity with the caregiver and the person with the disease, have a better understanding thereof. They also tend to have less negative attitudes towards persons with Alzheimer’s disease and are more willing to assist when needed. This can probably be ascribed to the fact that they might know the caregiver and the person suffering from the disease. The vast majority of the participants expressed the need for awareness about Alzheimer’s disease in the community. The influence of the communities’ understanding of Alzheimer’s disease on the caregiver reflects the complex relationship between individuals and their environments as proposed by the ecosystems perspective.

- **Sub-theme 2.2: Indigenous beliefs**

Lay conceptions of Alzheimer’s disease are influenced by the cultural perspective from which they are being viewed. For example, Faison and Armstrong (2003:227) assert that sorcery and witchcraft may be considered delusions in some cultures, but may be popular concepts in other cultures.
A recent study led by Lawrence, Samsi and Banerjee (2010) found that black Caribbean people with dementia feared being viewed as “crazy” or “mad” (Botsford et al., 2011:443). The concepts of sorcery, spiritual possession, and witchcraft are used to explain psychological symptoms among African Americans, Hispanics and American Indians with Alzheimer’s disease (Faison & Armstrong, 2003:27).

Benade (2012:76), Borochowitz (2011:32) and Jorm (2000:397) are of the opinion that in African rural communities, Alzheimer’s disease is an illness that is still highly stigmatised, shrouded in myth and, in many communities, associated with witchcraft and possession by evil spirits. Such individuals may unfortunately be killed prematurely by stoning in the view of Ogunniyi et al. (2005:260). This often results in the alienation of persons suffering from the disease (Gureje, 2007:12).

Seven study participants reported that the community associates Alzheimer’s disease with witchcraft and spiritual possession. The following responses are indicative of their experiences:

“Sometimes, some of them say it could be ancestral or that it is ancestral spirits causing the disease.”

“I think that the community think about those things (witchcraft and possession). They come to me and ask me why I don’t take him to the sangoma.”

“Yes, they say there are demons in him.”

“Most people in the community say he is bewitched.”

“When she walks around at night, the people think she is a witch.”

When asked whether they believed that Alzheimer’s disease is caused by witchcraft, spiritual possession or ancestral influences, six participants indicated that they believed so whilst one participant indicated that she was uncertain. The participants responded as follows:
“The ancestors are not happy with goggo. That is why she is sick.”

“Maybe the ancestors, the people that have passed on, maybe they got something to do with it.”

“Sometimes I think so, because the Bible says that there was that one man who was having the seven demons and until they pray for him and then the demons go to the pigs.”

“I think that it might be a witch. The problem is from his mother because she is saying that during the birth time, he didn’t come like any other children because he came at the back and they think they were bewitching the mother.”

It is evident that a large proportion of the population living in black rural communities associates Alzheimer’s disease with witchcraft and the possession of evil spirits. This finding correlates with the proposition of Benade (2012:76) that Alzheimer’s disease in rural areas is often ascribed to witchcraft. From an ecosystems perspective, the findings suggest that cultural and traditional beliefs shape the way in which individuals view medical conditions such as Alzheimer’s disease.

- **Sub-theme 2.3: Traditional treatment practices**

A growing body of literature suggests that traditional healing is a common practice in South African rural communities. Traditional medicine, as opposed to Western medicine, is the first choice of treatment for many South Africans who suffer from psychiatric conditions such as Alzheimer’s disease (Kalula et al., 2010:229; Mavundla, 2009:359; Mbwayo et al., 2013:134; Peltzer, 2001:4). Keeton as quoted by Ross and Deverell (2010:36) states that eight out of every ten black South Africans rely on traditional medicine alone, or in combination with Western medicine.

Six participants reported that traditional healers such as sangoma’s and prophets have, according to their knowledge, treated the persons with Alzheimer’s disease. When asked about the diagnoses and treatment offered by traditional healers, the participants shared the following experiences:
“We have been to a traditional healer many times. They take a lot of money, R5000 to R10 000. I have to give them the money, but nothing gets better. I also have to give the sangoma a goat, chickens and blankets. The sangoma says she is bewitched. They give her a potion to drink but it does not help.”

“His brother took him to a prophet. The prophet gave him a rope and some water. He had to pray with the rope and the water. They pray over the water and he must drink it then they put some ashes and he must wash in it. It did not help.”

“I have been to a sangoma many times but now I haven’t got the money. The sangoma charges R1500. The sangoma told me that he has a baboon heart. The sangoma pour muti in the water for him to bath and then they put the other one in the food and they make a smoke that he must inhale. But we don’t see any change so we stopped going. The other sangoma’s told me he is crazy.”

“I took him to the traditional healer three times. The traditional healer said he must go to the graveyard to talk to his ancestors. The traditional healer did not give him any medicine.”

Regardless the fact that some participants indicated that they do not believe in traditional healers, the findings show that traditional healers are considered as important role players in the treatment of Alzheimer’s disease in rural communities. However, the participants did not indicate that the treatment offered by traditional healers was effective for the treatment of the disease. The finding that more than half of the participants resorted to traditional healers for the treatment of Alzheimer’s disease correlates with literature which suggests that black South Africans often rely on complementary medicine or traditional healing for the treatment of Alzheimer’s disease (Kalula et al., 2010:229; Mbwayo, 2013:134). The findings demonstrate the interrelatedness between cultural beliefs and help seeking behaviour as rooted in the theoretical framework used in this study.
• **Discussion of theme 2**

The participants had diverse views pertaining to the knowledge and attitudes of the community about Alzheimer’s disease. Some participants felt that community members understand the condition, whereas others felt that the community should be made aware of the disease. Neighbours seem to be more understanding and supportive than other community members.

The association between Alzheimer’s disease and witchcraft was found to be prominent among rural community members and Alzheimer’s caregivers. Ancestors were also believed to have played a role in causing the disease. This finding correlates with literature, which indicates that Alzheimer’s disease in black communities is often linked to witchcraft and possession of evil spirits. It was also found that the majority of persons with Alzheimer’s disease have been treated by traditional healers or prophets with varying diagnoses and treatment methods. However, none of the participants reported that the treatment offered by traditional healers was effective in treating the disease. These findings are consistent with the ecosystems perspective, where the cultural context of individuals influences the way in which they experience life situations and their reactions to situations.

### 3.8.2.3 Theme 3: Caregivers’ understanding of Alzheimer’s disease

The focus of this theme is on the caregivers’ understanding of Alzheimer’s disease. The theme is divided into four sub-themes, which explores the understanding of caregivers of Alzheimer’s disease as a medical condition, the causes and symptoms of the disease and the medical treatment and prognosis thereof.

• **Sub-theme 3.1: Alzheimer’s disease as a medical condition**

Literature demonstrates that caregivers of persons with Alzheimer’s disease often have poor knowledge of the disease (Carpenter et al., 2011:121; Hughes et al., 2009:109).

In this study, participants were asked what they thought was wrong with the person who suffers from Alzheimer’s disease. Some participants indicated that the person suffered from some form of mental illness. The other participants had different explanations for the condition. Their responses were as follows:
“He is stressed.”

“Now that I know more about the disease, I know it is Alzheimer’s.”

“I don’t know what is wrong with him. I only know that he has changed.”

“Memory loss. Forgetting everything. If she puts something (away), then she forgets and sometimes she feels like someone is attacking her, but there is no one in the house. She says: Don’t tell anyone, don’t tell them that I am here, and don’t shout there is someone here.”

“She is mentally ill.”

“Alzheimer’s, and the sugar, and his blood pressure. This is what is hassling him.”

“I don’t know, I think it is sorcery.”

“He longs for his wife which is deceased. He thinks too much.”

In a study among 1381 caregivers, Tang, Harary, Kurzman, Mould-Quevedo, Pan, Yang and Qiao (2013:121) established that 62.9 percent of caregivers reported that they had a poor understanding of dementia. This lack of knowledge, according to Borrayo, Goldwaser, Vacha-Haase and Hepburn (2007:489), deprives caregivers of the necessary information to anticipate and cope with the progressive deterioration in cognitive and physical functioning that their older relative is likely to experience. In addition, a lack of knowledge can negatively affect appropriate help seeking (Hughes et al., 2009:100; Jang et al., 2010:419). Despite the general lack of knowledge, literature proposes that caregivers have the desire for general information to be coupled with facts, explanations and advice about the disease (Washington et al., 2011:40).

The findings show that the level of understanding of Alzheimer’s disease as medical condition varies among rural caregivers. Not all caregivers view Alzheimer’s disease
as a medical condition, but attribute the disease to other factors such as stress, loneliness and witchcraft. This finding highlights the need for caregiver education to overcome the cultural obstacles facing vulnerable populations.

- **Sub-theme 3.2: Causes of Alzheimer’s disease**

  The findings of the study illustrate that black rural caregivers of persons with Alzheimer’s disease have limited knowledge of the medical causes of the disease. Only two participants indicated that Alzheimer’s disease could be caused by advanced age or brain injury. When asked about the causes of Alzheimer’s disease, the participants offered the following responses:

  “The family members that all passed on that’s why this thing is affecting her mentally. She went to her sister’s funeral in Johannesburg, because she is originally from Johannesburg. When she came back it started.”

  “Perhaps it was the death of his wife.”

  “Because he lost his wife and his child disappeared and his brother passed away. I think he is stressed.”

  “I just think he is crazy.”

  “Maybe someone did something to him. I think it is witchcraft.”

  “I think that perhaps he had a problem in his family and then he developed stress.”

  “He thinks too much.”

  The findings are consistent with a South African study conducted by Mavundla et al. (2009:363) on caregiver experience in mental illness, which revealed that many participants did not understand the causes of the illness of the person to whom they provide care. A US-based study yielded similar results and found that Latino’s believe that people develop Alzheimer’s disease because they think too much, are
stressed out, or have personality issues (Sherry & Cruz, 2014:p295). Hinton et al. (2005:1407) found similar results. The findings further correlate with the opinion of Belgrave et al. (2004:202) that lay explanations of Alzheimer's disease are often tied to ethnicity and/or culture. The authors cite numerous explanations among various ethnic, cultural and racial groups. Such explanations include worries, stress, high blood pressure, spells, tragic losses and family responsibility.

It is noticeable from the study that rural caregivers lack understanding of the causes of Alzheimer's disease and that the social and cultural environment, from an ecosystems perspective, influences the actions, beliefs and choices of the individual.

- **Sub-theme 3.3: Symptoms of Alzheimer's disease**
  The participants were asked to describe the symptoms exhibited by the Alzheimer's disease sufferer. The symptoms identified by the participants are summarised in Table 3.6 according to the four major symptom categories, i.e. memory impairment, behavioural and personality changes, intellectual impairment and physical changes.

<table>
<thead>
<tr>
<th>ALZHEIMER'S DISEASE SYMPTOM CATEGORY</th>
<th>ALZHEIMER'S DISEASE SYMPTOMS IDENTIFIED BY PARTICIPANTS</th>
<th>PERCENTAGE OF PARTICIPANTS WHO IDENTIFIED SYMPTOM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory impairment</td>
<td>• Inability to recall names</td>
<td>73%</td>
</tr>
<tr>
<td></td>
<td>• Inability to recognise familiar persons</td>
<td>82%</td>
</tr>
<tr>
<td></td>
<td>• Memory loss</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>• Misplacing items</td>
<td>55%</td>
</tr>
</tbody>
</table>

*Table 3.6: Alzheimer's disease symptoms identified by participants*
<table>
<thead>
<tr>
<th>ALZHEIMER’S DISEASE SYMPTOM CATEGORY</th>
<th>ALZHEIMER’S DISEASE SYMPTOMS IDENTIFIED BY PARTICIPANTS</th>
<th>PERCENTAGE OF PARTICIPANTS WHO IDENTIFIED SYMPTOM</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Behavioural and personality changes</strong></td>
<td>• Aggression</td>
<td>91%</td>
</tr>
<tr>
<td></td>
<td>• Undressing</td>
<td>64%</td>
</tr>
<tr>
<td></td>
<td>• Wandering and getting lost</td>
<td>91%</td>
</tr>
<tr>
<td></td>
<td>• Suspicious behaviour</td>
<td>82%</td>
</tr>
<tr>
<td></td>
<td>• Inappropriate dressing</td>
<td>46%</td>
</tr>
<tr>
<td></td>
<td>• Poor hygiene and refusing to bath</td>
<td>91%</td>
</tr>
<tr>
<td></td>
<td>• Sleep disturbances</td>
<td>73%</td>
</tr>
<tr>
<td></td>
<td>• Hallucinations and delusions</td>
<td>45%</td>
</tr>
<tr>
<td><strong>Intellectual impairment</strong></td>
<td>• Inability to communicate</td>
<td>55%</td>
</tr>
<tr>
<td></td>
<td>• Inability to perform motor functions</td>
<td>73%</td>
</tr>
<tr>
<td></td>
<td>• Inability to perform complex tasks</td>
<td>73%</td>
</tr>
<tr>
<td><strong>Physical changes</strong></td>
<td>• Frailty</td>
<td>82%</td>
</tr>
<tr>
<td></td>
<td>• Incontinence</td>
<td>55%</td>
</tr>
</tbody>
</table>

All the participants were able to identify the symptoms of Alzheimer’s disease. Tsolaki, Paraskevi, Degleris and Karamavrou (2009:23) found that the caregiver is very often the first person to observe the symptoms of Alzheimer’s disease. The same authors found that the first symptoms reported were memory problems, deteriorating behaviour, changes in personality and depression.

In a recent study led by Koehn, McCleary, Garcia, Spence, Jarvis and Drummond (2011:47), caregivers reported a diversity of experiences about the early symptoms of cognitive deficits in persons with dementia. These included repetitious questioning, problems with name recall, misplacing money, going to the kitchen instead of the bathroom and leaving the tap on. However, Werner (2003:1029) cites that research has found that caregivers have difficulty in differentiating memory problems that are part of normal ageing from those that are predictors of Alzheimer’s disease.
Findings suggest that rural caregivers, based on their caregiving experiences, are able to identify the symptoms of Alzheimer’s disease. The correct understanding of disease symptoms can facilitate the early detection of the disease, which in turn can improve the benefits of treatment (Werner, 2003:1030).

- **Sub-theme 3.4: Medical treatment and prognosis of Alzheimer’s disease**

Despite all scientific efforts, there are no effective medicines available for the prevention and treatment of Alzheimer’s disease. Current treatments are only symptomatic in nature, attempting to counterbalance the neurotransmitter disturbance and to control the psychotic and behavioural symptoms of the disease (Kalaria et al., 2008:812; Qadi et al., 2007:105; Yiannopoulou et al., 2013:19). There is currently no single cure for Alzheimer’s disease (Appel et al., 2009:13; Misra & Medhi, 2013:831; Sanphui et al., 2013:78842).

Participants were asked to explain what medical treatment, in their view, would help the person with Alzheimer’s disease. Only three participants indicated that medical treatment would benefit the person with Alzheimer’s disease. The following responses were received:

“*If maybe she can go to the hospital or if maybe she can get some tablets or medicine. That is something that maybe can help.*”

“*Maybe if he can get a wife. Maybe that can help him.*”

“I don’t think there is any treatment. I have even tried to have people to pray for him in the church and there has been no change.”

“I also know that there is no treatment for it. It is incurable and you just have to try to understand him, agree with him, whatever, so that he can just be calm.”

“I don’t think there is any treatment that can help him, because she has already gone to the clinic and the tablets have not helped him.”
“The doctors told me there is no medication to help her. No medicine for the cure. They only give her (medication) for the pain.”

“No, there is no treatment. He does take his medication, but there is no change.”

“If there is a doctor that can help, I will appreciate it because there is no medicine that can help him, except if we talk to him. We must help him to think right.”

“I think the doctor will help. She improved the time when she took her tablets.”

The participants were also asked to explain whether they think there is a cure for Alzheimer’s disease. One participant said that he does not know. Six participants indicated that the disease is curable, while four participants reported that there is no cure.

The participants hence showed insufficient knowledge about the prognosis and medical treatment available for the management of Alzheimer’s disease. This finding corresponds with empirical studies, which revealed that at time of diagnostic disclosure, caregivers received little information about dementia and prognosis. One study showed that less than one third of caregivers were informed of the treatment options available to them at this time (Ducharme, Lévesque, Lachance, Kergoat, Legault, Beaudet & Zarit, 2011:484). Brodaty and Green (2002:894) are of the opinion that caregivers have several important roles in the pharmacological management of Alzheimer’s disease. These include the role of decision-maker and consent-giver, as well as ensuring compliance with and monitoring effects and adverse events of drug treatment. This notion implies that caregivers should at least have some understanding of the medical treatment available for the management of Alzheimer’s disease.
Discussion of theme 3
This theme revealed that rural caregivers, in general, have inadequate knowledge of Alzheimer’s disease as a medical condition. The participants had various explanations for the condition of the person suffering from the disease. Although half of the participants recognised Alzheimer’s disease as a mental illness, others attributed the disease to stress, witchcraft and longing for a deceased spouse. Only two participants indicated that Alzheimer’s disease is associated with advanced age or brain injury. The other participants stated that the disease is caused by factors such as the death of a family member, stress, witchcraft, family problems or that the person thinks too much. Although all the participants successfully identified the most common symptoms of Alzheimer’s disease, based on their caregiving experiences, the vast majority showed very little insight into the prognosis and medical treatment of Alzheimer’s disease. Literature suggests that this lack of knowledge can negatively affect help seeking and the ability of caregivers to deal with the progressive nature of the disease. From an ecosystems perspective, it is evident that cultural beliefs influence the understanding of Alzheimer’s disease as a medical condition.

3.8.2.4 Theme 4: The impact of Alzheimer’s disease on the caregiver
Alzheimer’s disease affects quality of life for both the patient and caregiver in profound ways, as caregiving is an inherent part of managing the disease. Literature shows that Alzheimer’s disease can have overwhelming consequences and negative outcomes for caregivers, often resulting in caregiver burden. Hepburn, Tornatore, Center and Ostwald (2001:450) profoundly state: “family caregivers, particularly those caring for demented relatives, pay an added price: they provide care at the expense of their own physical and mental health, contending with added stresses in the family and risk social isolation.” In contrast, recent studies have documented positive outcomes associated with Alzheimer’s caregiving (Lee & Choi, 2012:424; Mavundla et al., 2009:355). This theme explores the physical, psychological and social impact of Alzheimer’s caregiving on the caregiver as well as the positive outcomes associated with caregiving.
Sub-theme 4.1: Physical impact of caregiving

The negative outcomes associated with caregiving are well documented and include decreases in physical health (Alzheimer’s Association, 2013:225; Lahaie et al., 2012:252; Potgieter & Heyns, 2006:548; Roepke et al., 2011:59; Sörensen & Conwell, 2011:491). These health outcomes, as discussed in section 2.7.3.1, include general decline in physical health, cardiovascular disease, reduced immune function and hypertension and, according to Bevans and Sternberg (2012:399), can contribute to early death.

In exploring the physical impact of caregiving, participants were asked to articulate their perceptions of their own physical health. They were also asked to explain their views about the effects of caregiving on their health. Ten participants described their own health as poor. Seven participants reported that they visit a health clinic at least once per month. Eight participants indicated that caregiving negatively affects their physical health status. The most frequently self-reported health conditions include hypertension, body aches, headaches, fatigue, sleep disturbances, HIV/AIDS and diabetes. When asked to elaborate, the participants shared the following views:

“I have high blood. I take medication for that. At night, I feel my body is vibrating then I take Panado and then it goes away. The doctor says I must not take fatty food. I get headaches. I always feel tired. I get flu often.”

“I feel pain and a headache. I feel it under my back and under my breasts. I get tired.”

“I have high blood and had a stroke. I have this pain from the breasts every month and it is difficult to breathe. I often get sick.”

“I have sugar and high blood. It affects my health, as I am never free. He (the person with Alzheimer's disease) would get up and break the windows. Sometimes when I am sleeping they call me, even in the night, because he is on the road and I have to go and fetch him.”
“It affects my health. Most of the time I do not sleep because I have to look at him at night when he does not sleep. I am HIV positive and have high blood. I often get sick.”

“I get so tired quickly and I am losing weight as I am worried about him.”

The findings of this study demonstrate that dementia caregiving frequently results in negative physical health outcomes for rural caregivers. These findings are similar to those of other studies that examined the physical health outcomes of dementia caregiving.

Shaw as cited in Chattillion et al. (2013:794) found that dementia caregivers had a 67 percent increase in risk of developing hypertension as compared with non-caregiving controls. In particular, dementia caregiving has been associated with heart problems (Holland et al., 2011:334). In another study, Shulz and Beach as cited in Losada, Márquez-González, Knight, Yanguas, Sayegh and Romero-Moreno (2010:193) established that caregivers who experience caregiver strain had mortality risks that were 63 percent higher than non-caregiving controls. Do et al. (2013) explain that caregivers often experience physical pain and poor self-assessed health as caregiving involves physical effort, lifting other people and performing physical chores. In addition, Alzheimer’s caregivers were found to have reported a higher number of physical symptoms and a higher risk of reporting chronic conditions (Kang & Marks, 2014:4).

There is insufficient literature that explores the physical health outcomes of Alzheimer’s caregiving in black rural communities. In the United States, studies have found that although African American caregivers tend to receive more instrumental support from family and friends than white caregivers do, they report greater negative consequences of caregiving for their physical health than do white caregivers (Kaufman, Kosberg, Leeper & Tang, 2010:254). Brinda et al. (2014:5) report that, with extended hours of caregiving, these caregivers may develop sleep disturbances and chronic diseases. This study suggests that Alzheimer’s caregiving is associated with negative health outcomes among rural caregivers and reflect the social conditions of such caregivers.
Sub-theme 4.2: Psychological impact of caregiving

Alzheimer's caregivers often experience significant psychological suffering. Decades of research have shown that these caregivers are highly stressed, with significant implications for physical and mental health (Cheng et al., 2012:71). Psychological symptoms described in literature include frustration, depression, anxiety, anger, guilt, somatic symptoms, isolation and conflicts in relationships (Alzheimer's Association, 2013:223; 2005:475; Bauer et al., 2001:329; Theofilou, 2012:2; Vitaliano et al., 2004:14).

The study endeavoured to determine the psychological impact of caregiving on rural caregivers. Participants were asked whether they often feel depressed; experience feelings of loneliness and stress; and whether they experience caregiving as a burden. The results generated were consistent among the participants. Nine of the eleven participants reported that they often feel depressed. Eight participants viewed caregiving as a burden. Nine participants indicated that they experience feelings of loneliness whereas eight participants regarded Alzheimer’s caregiving as being stressful. The following phrases are indicative of the psychological consequences of caregiving experienced by the participants:

“I start to suffer and struggle a lot looking after her. It makes me depressed to think what is going to happen to her when I die. It is a burden for me to look after her.”

“I get stressed because I am supposed to look after my mother and look after the house. My mother sometimes gets out of the window and she can fall out of the window and hurt herself. I sometimes feel tired. I do not want to talk to someone. It makes me feel sad all the time. It makes me lonely and to feel overcrowded, because I have to take care of Goggo even though there are other relatives and other children. I have to take care of her alone.”

The study results show similarities with the findings of other studies cited in literature. Theofilou (2012:2), for example, confirms that depression, anxiety and stress are common among caregivers of patients with Alzheimer’s disease, and numerous studies have investigated how these emotions affect caregiver’s quality of
life and burden. The behavioural and psychological symptoms associated with Alzheimer's disease are a significant cause of caregiver burden (Ornstein, Gaugler, Devanand, Scarmeas, Zbu & Stern, 2013:1278). Nichols, Martindale-Adams, Burns, Graney and Zuber (2011:353) postulate that caregivers frequently lack the skills to manage patient behaviours and their own stress. Caregivers’ lack of skills can lead to adverse psychological consequences such as depression, anxiety, sleep disturbance and hospitalisation.

Depression is associated with symptoms of sad mood, loss of interest, change in appetite, difficulty sleeping or oversleeping, agitation, loss of energy, feelings of worthlessness, difficulty thinking and suicide ideations (Lander & Cuellar, 2013:14). In addition, depression is closely linked to caregiver’ loneliness (Vellone et al. (2007:224). Schoenmakers et al. (2010:193) report that the depression rate in caregivers of elderly patients with dementia range from 30 percent to 80 percent, depending on the study population and recruitment method. A systematic review conducted by Cuijpers as quoted by Joling, Smit, van Marwijk, van der Host, Scheltens, Schulz and van Hout (2012:298) established that almost half of the caregivers developed a depressive disorder within a year. Schoenmakers et al. (2010:193) found that women are more frequently depressed than men and that Americans of black African origin feel less depressed than their white counterparts do. Rural caregivers reported higher depression levels than urban caregivers (Lander & Cuellar, 2013:16).

Alzheimer’s caregiving is associated with loneliness and social isolation. Vitaliano et al. (2011:902) refer to various studies which found that social interaction with family and friends may decrease due to of the behavioural problems displayed by the person with Alzheimer’s disease. Caregiving may reduce participation in community activities, because of caregiving demands. These changes eventually result in a smaller social network, less opportunity to engage with others, and greater social isolation.

It is evident from the results yielded by the study that Alzheimer’s caregiving is detrimental to the emotional and psychological wellbeing of caregivers. These caregivers, in view of the theoretical framework provided by the ecosystems
perspective, exist within families, communities and neighbourhoods; therefore, social support and social participation are imperative for the wellbeing of caregivers.

- **Sub-theme 4.3: Social impact of caregiving**

Providing care to the person with Alzheimer’s disease can have a negative effect on the social functioning of caregivers. Negative outcomes are often associated with role conflict and role-overload, family dysfunction, restricted social activities and the lack of social and emotional support. Financial and employment issues are associated with caregiver burden among rural Alzheimer’s caregivers.

This study explored various aspects of social functioning. Eight participants reported that they do not have enough time for themselves due to caregiving demands. Five of the eleven participants indicated that they do not have enough time for their families and eight participants felt that they are neglecting their friends. This results in feelings of social isolation and a perceived lack of social support. Two of the six participants who are married experienced negative effects on their marital relationships. Seven participants explained that they experience financial difficulties because of caregiving. None of the participants indicated that they are employed on a full-time basis. Seven participants are in receipt of government grants. None of the participants receive any remuneration for their caregiving tasks. The findings indicate that Alzheimer’s caregiving, to some extent, affects the social functioning of rural caregivers. The participants explained their experiences as follows:

“The relationship changed. Before she was my wife now she is more a mother and granny figure to me. It feels as I am not married any longer.”

“I don’t have time for friends, because I must look after my house and take care of goggo. I never see my friends. When they come here, I have to run after my mother all the time and can’t talk to them.”

“I don’t have any time for myself, because there is no one else to look after him. Looking after him is a full-time job. I don’t get time to do anything else. It makes me tired.”
“I suffer without money. I have to look at her all the time. I cannot go and find a job. Sometimes we don’t have food to eat or money for the transport to the clinic.”

“I get no support from my neighbours or the community. They don’t care. Nobody cares. I feel very alone in this.”

“Most of the time I feel lonely. I feel lonely especially when I have a problem with my father. The family don’t support me. If I complain they say it’s my fault.”

The findings are consistent with existing literature investigating the social consequences of Alzheimer’s caregiving. The strains experienced by caregivers carry over to other roles and relationships. Pinquart and Sörensen (2011:1) explain that Alzheimer’s caregivers often have conflicting responsibilities, such as careers or children who require support and attention. Whereas some may experience more role conflicts, increasing their risk for role-overload, others find that the other roles are complementary to their caregiving responsibilities. Roberto and Jarrott (2008:103) assert that role conflict commonly distress caregivers, who report forfeiting other activities and relationships to satisfy their relative’s care demands and the expectations of other family members. The same authors report that caregivers associated greater role conflict with a sense of identity loss in the caregiving role.

In a study on caregiver experiences in South Africa, Mavundla et al. (2009:361) found that caregivers indicated that they suffer social isolation; they cannot attend church services, funerals, and other important traditional functions, because of their involvement in the support of the care receiver.

The financial demands necessitated by caregiving strains further challenge the wellbeing of caregivers. Roberto and Jarrott (2008:102) found that 59 percent of caregivers juggle employment with caregiving responsibilities in order to meet their own financial obligations and the cost of caring for their elderly relatives. Another study cited by Timmermann (2010:21) found that 43 percent of American caregivers indicated that caregiving is a financial hardship for them. This figure is expected to
be higher in rural areas where unemployment and poverty are prevailing factors. In a rural study, Mavundla et al. (2009:361) found that financial constraints were the major challenge to most of the participants in providing care to their ill family members.

Most researchers consider the support of friends and family an important aid to individuals’ adjustment during or following stressful life events. However, a study by Smerglia, Miller, Sotnak and Geiss (2007:213) found that most of the time, caregivers of older persons reported that social support does not have a significant positive impact on adjustment. Support from family and friends are not necessarily helpful to persons filling the stressful role of caregiver for an older relative. This is however contradictory to studies described by Huang, Sousa, Perng, Hwang, Tsai, Huang and Yao (2009:503) which found that social support may reduce the effect of caregiving stress.

The findings suggest that rural Alzheimer’s caregivers have limited time for themselves, their friends and their families, which result in social isolation and a perceived lack of social support. They are also overwhelmed by the different roles that they have to perform such as being a parent or a spouse. The caregivers further reported that they experience financial difficulties because of caregiving and that they are dependent on social grants. Because of the caregiving demands, caregivers are not in a position to enter fulltime employment that contributes to the financial strain that they experience. These findings correlate with the ecosystems perspective, which emphasises the functioning of individuals within the social and economic context of the community.

- **Sub-theme 4.4: Positive aspects of caregiving**
  Caregiving research has historically focused on understanding the negative consequences of caregiving with significantly less focus on the positive aspects of caregiving (Semiatin & O’Connor, 2012:683). Positive aspects of caregiving have been identified in a number of ways, but they are typically defined as the rewards and satisfaction derived from the caregiving relationship (Kramer as quoted by Hilgeman, Allen, DeCoster & Burgio, 2007:361). Many caregivers find meaning in providing care to a loved one, feel more useful, gain new skills, and experience other
benefits from giving back to those who have helped them in the past (Roth, Perkins, Wadley, Temple & Haley, 2009:680).

Hodge and Sun (2012:689) argue that caregiving is experienced subjectively. In the same way that negative attributions can lead to detrimental outcomes, beneficial attributions of the caregiving experience can produce positive aspects of caregiving. In other words, positive aspects of caregiving occur as the subjective experience of caregiving is interpreted through a salutary lens.

Burden and positive gains appear to be two independent aspects of the caregiving experience. Cheng et al. (2012:72) explain that positive gain is not simply the absence of burden; in fact, it is hardly likely that a caregiver would achieve high positive gain without being placed in a challenging situation in the long term.

During the research interviews, participants were asked whether they experience providing care to persons with Alzheimer’s disea...
“I enjoy looking after goggo. I think it is a blessing. I am very, very happy. She is my husband’s mother and I am supposed to look after her. I am helping the family.”

“He was a good husband to me and to my child when he was healthy. Why should I then not look after him? God wants me to look after him. I am making God happy too.”

The findings are consistent with empirical studies cited in literature. Jones, Winslow, Lee, Burns and Zhang (2011:12), for example, refer to a study which revealed that Chinese and Filipino American women caregivers were challenged by the demands of multiple roles, but rewarded by satisfaction from giving back to their parents in gratitude for what they had done for them. Another study among African American and white caregivers of family members with dementia found meaning in the caregiving experience, and caregivers with higher levels of meaning had lower depression scores (Jones et al., 2011:12). In support of these findings, the ecosystems perspective postulates that families and communities in which caregivers function, influence their experiences.

In spite of the negative consequences of Alzheimer’s caregiving, the study demonstrates that rural caregivers often experience caring for a person with Alzheimer’s disease as rewarding and as an opportunity to give back to the community or a loved one suffering from the disease.

- **Discussion of theme 4**
  The results of this theme demonstrate the effects of Alzheimer’s caregiving on the physical, psychological and social functioning and wellbeing of rural caregivers providing care to persons with Alzheimer’s disease. The study found that rural caregiving is associated with negative health outcomes. The vast majority of participants self-assessed their physical health as poor. The most frequently reported health problems include hypertension, diabetes, HIV/AIDS, fatigue, headaches, sleep disturbances and generalised body aches.
Alzheimer’s caregiving influences the psychological wellbeing of rural caregivers. The study revealed that the majority of participants viewed caregiving as a burden. High levels of stress and depression associated with caregiving were reported. In addition, the majority of participants experienced feelings of loneliness. The findings are consistent with research that indicates that Alzheimer’s caregiving is associated with poor quality of life resulting in caregiver burden.

The study further showed that Alzheimer’s caregiving is detrimental to the social functioning of rural caregivers. The financial implications of caregiving were reported as a major challenge as the majority of participants are dependent on social grants with none of them receiving any caregiving remuneration. The participants further reported that they have limited time for themselves, their families and their friends, resulting in social isolation and perceived lack of social support, which from an ecosystems perspective, affect their social functioning within the context of the family and community.

Despite the caregiver burden experienced by the participants, the positive outcomes of Alzheimer’s caregiving were explored. The majority of participants indicated that they experience Alzheimer’s caregiving as rewarding, as it affords them the opportunity to give something back to the community, their families and the person in their care. This finding is supported by literature indicating that dementia caregivers often find meaning in the caregiving experience (Alzheimer’s Association, 2013:223; Connell et al., 2001:180; Tarlow et al, 2004:439).

3.8.2.5 Theme 5: Support services in the community

Alzheimer’s caregiving is influenced by the various ecosystems of individuals, including community support. Community care is the most common solution for Alzheimer’s sufferers if they have somebody to take care of them. Family members often prefer community care, even at more advanced stages of Alzheimer’s disease (Eloniemi-Sulkava, Notkola, Hentinen, Kivelä. Sivenius & Sulkava, 2001:1282). Community support services can complement the care provided by Alzheimer’s caregivers by sharing in the overall caregiving load. Moreover, caregiver-specific services have the potential to empower caregivers with knowledge and skills, and provide emotional support (Lim, Goh, Chionh & Yap, 2012:1571). This theme
explores the needs and experiences of rural caregivers relating to community support services. The theme is divided into seven sub-themes that focus on a range of community support services.

- **Sub-theme 5.1: Health care services**

Fortinsky (2001:35) explains that, for most family caregivers of persons with dementia, physicians are the first and only contact in the health care system, both before and at the time a diagnosis of Alzheimer's disease is made. The same author further asserts that from a health care system perspective, physicians are in a unique position to help caregivers reduce the risk of adverse outcomes by carefully explaining the dementia disease process, advising how to manage symptoms as they occur, and linking caregivers with appropriate community support services. However, this is not always the reality in rural communities in Mpumalanga. Borochowitz (2011:32) supports this argument by citing that older persons, and particularly those with dementia, are not a health care priority in South Africa.

All the participants in this study indicated that they are dependent on public health care services provided by government. Six of the eleven participants reported they make use of clinic services only, while four participants indicated that they make use of both clinic and hospital services. Only one participant reported that the person with Alzheimer's disease does not make use of health care services. Eight participants said that the person with Alzheimer's disease visits the hospital or clinic on a monthly basis. Two participants indicated that they only visit the clinic or hospital when needed. Seven participants reported that a professional nurse attends to the person with Alzheimer's disease, while only one participant indicated that a physician sees the person. The participants further reported that the waiting time to be attended to by a physician or professional nurse at public health care facilities varies from two to seven hours. The average waiting time reported is 4.88 hours.

In order to determine the accessibility of health care facilities, the participants were asked to indicate the distance to the nearest clinic or hospital, the mode of transport and the transport costs involved. The results are summarised in Table 3.7.
Table 3.7: Distance to nearest health care facility, mode of transport, and costs involved

<table>
<thead>
<tr>
<th>PARTICIPANT</th>
<th>DISTANCE TO NEAREST HEALTH CARE FACILITY</th>
<th>MODE OF TRANSPORT</th>
<th>COSTS INVOLVED</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8 km</td>
<td>Public transport</td>
<td>R24 per person</td>
</tr>
<tr>
<td>2</td>
<td>30 minutes by foot</td>
<td>Walking</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>1½ hours by foot</td>
<td>Walking</td>
<td>-</td>
</tr>
<tr>
<td>4</td>
<td>3 km</td>
<td>Own vehicle</td>
<td>-</td>
</tr>
<tr>
<td>5</td>
<td>2 km</td>
<td>Walking</td>
<td>-</td>
</tr>
<tr>
<td>6</td>
<td>5 km</td>
<td>Public transport</td>
<td>R30 per person</td>
</tr>
<tr>
<td>7</td>
<td>200 m</td>
<td>Walking</td>
<td>-</td>
</tr>
<tr>
<td>8</td>
<td>3 km</td>
<td>Walking</td>
<td>-</td>
</tr>
<tr>
<td>9</td>
<td>5 km</td>
<td>Public transport</td>
<td>R45 per person</td>
</tr>
<tr>
<td>10</td>
<td>10 km</td>
<td>Public transport</td>
<td>R135 per person</td>
</tr>
<tr>
<td>11</td>
<td>4 km</td>
<td>Public transport</td>
<td>R10 per person</td>
</tr>
</tbody>
</table>

Table 3.7 illustrates that the distance to the nearest health care facility ranges from 200 metres to 10 kilometres. Half of the participants reported that they make use of public transport to access health care services whilst the other half indicated that they travel by foot. Public transport costs varied from R10 to R135 per person. Only one participant owns a vehicle. Public health services were found to be accessible for persons with Alzheimer’s disease and their caregivers, however, for some caregivers, transport costs are an additional burden.

The participants were asked to describe their experiences of the health care system, and more specifically, with the diagnosis and information received, and the attitude of health care professionals. Some of the participants responded as follows:
“Some say it is old age and some say it is not old age. It is all they say. They are OK towards us. Everything about my wife they ask me.”

“At the clinic, they don’t know about Alzheimer’s disease. They only check the blood pressure and sugar. When we get to the clinic, they (the medical staff) are already tired and they are aggressive to her (Alzheimer’s patient).”

“I myself don’t really want to go to the clinic. Even if you go there, you will find the queues and then they don’t treat the people at the same level. They will treat you as if you are nobody. That is why the other people end up coming home. I hate the clinic.”

“They (the medical staff) don’t tell me anything what is wrong. They just give him medication for the brain. I don’t like them (medical staff). The hospital is not good. People sleep on the bench. They say they have been there since yesterday. People even die there.”

“All they say what is wrong with goggo is the old age. Sometimes they (medical staff) take care of us, sometimes they just ignore us. You have to be patient. You wait four to five hours because of the lack of staff. Only to find there is only one sister who is busy with the pregnancies and the children. So you have to wait.”

“They never told me what is wrong with my grandfather. They treat him well and encourage him to take his medication.”

“We went to the clinic, but the clinic said we must go to the hospital. When we got to the hospital, the staff asked what is wrong with goggo? I said, I don’t know. They said they also don’t know and don’t know what medication to give her. They gave medication that makes goggo weak. I am not going back again.”

In general, the participants described their experience with the public health care system in a negative manner and reported that health care professionals provide
them with insufficient information about the diagnosis and management of Alzheimer's disease. Nevertheless, all the participants indicated that they would benefit from information about the symptoms and management of Alzheimer's disease.

The findings are consistent with the views of Kalula and Petros (2011:32) who state the following:

In Africa, medical doctors, largely at the primary care level, lack awareness of and training in treating dementia, and are found disinclined to investigate symptoms of dementia – or to refer patients with the symptoms for investigation. They too, simply ascribe the symptoms to old age. Nurses who screen such patients at the primary level do the same, and inform the patients that no medications are available for their particular ailment.

A research study by Mavundla et al. (2009:362) yielded similar results. They found that in rural areas, persons with conditions such as Alzheimer’s disease are not only rejected by the community, but also by health care professionals. The researchers established that caregivers are often frustrated by the lack of education from health professionals regarding their relative’s illness. In addition, the study found that caregivers experienced nurses as uninterested in, or apathetic to, assisting them.

It is evident that, although public health care facilities are accessible, many rural Alzheimer’s caregivers have negative views about the public health care system and are not satisfied with the attitudes of health care professionals and the information received about the diagnosis and management of the disease. The theoretical framework of this study indicates that access to health care services and the attitudes of health care professionals can influence the beliefs and choices of caregivers in terms of medical health seeking behaviour.

- **Sub-theme 5.2: Home-based care services**
  Many persons with Alzheimer’s disease are in need of long-term care, because of disabilities in activities of daily living, rather than a need for 24-hour skilled medical
care (Sands, Xu, Weiner, Rosenman & Thomas 2008:450). The need for home-based care has arisen as a result of the increasing demand for health care services and the escalating cost of these services (Ncama, 2005:34).

The aim of home-based care is to provide effective and affordable community-based care and support (Van Rensburg, 2004:426). Such services include physical, emotional, spiritual and palliative care to ill patients in their own natural environment (Mundia, 2008:21) and are provided by formal and informal caregivers (Hunter, 2007:232). However, the vast majority of home-based carers are volunteers who receive little or no training or support, performing their duties in adverse conditions (Campbell & Foulis, 2004:5). Borochowitz (2011:33) emphasises the need for home-based carers to be trained and educated in order to render the care required by persons with Alzheimer’s disease.

In this study, half of the participants indicated that they are supported by home-based care services, whereas the other half indicated that they would benefit from such services. These services are provided by non-governmental community-based organisations. When asked about the support they receive from the home-based carers, the participants responded as follows:

“They cook when goggo says she is hungry and they clean the kitchen. They come twice per week.”

“They just come to ask questions and write things down. They check the blood pressure again and talk to her. They just come sometimes and ask how many people stay in the house and which tablets you are taking. They don’t do anything.”

“I don’t think that the home-based carers can help. They don’t help people.”

“They come every week. They even phone me. They help me in the situation and tell me how to deal with her (person with Alzheimer’s disease). They explain the disease and tell me to be patient with the old lady and you must do this and must not do this.”
“They come on Monday, Wednesday and Friday. They help me a lot. They bath him and they give me a chance to rest. They give him his medication and then his porridge. Then they walk with him for exercise.”

Mundia (2008:21) confirms that up to 90 percent of illness care and close to 80 percent of the deaths in developing countries take place in the home. Home-based care services are mainly provided by non-governmental organisations, community-based organisations, faith-based organisations and concerned individuals (Cullinan in Ncama, 2005:33). Ncama (2005:38) emphasises that home-based care services are poorly funded and mainly left to non-governmental organisations to run, which often lack infrastructure and capacity.

The findings of the study show that home-based care services are available to most persons with Alzheimer’s disease in rural communities. Such services can provide much needed support to Alzheimer’s caregivers and, as a result reduce the burden of care experienced by these caregivers.

- **Sub-theme 5.3: Respite care**

In a needs assessment led by Theis and Deitrick (in Theis, Moss and Pearson, 1994:32) to learn what caregivers wanted in the way of interventions, it was found that most caregivers wanted relief or respite from the caregiving situation instead of support groups or educational groups. Theis et al. (1994:32) define respite care as “the planned, ongoing, or periodic provision of caregiving support services to a dependent elderly person and caregiver in the family home or in an institutional setting.” Respite resources in the community may be critical in lessening the burden of caring for an individual with a chronic mental disorder. Lazarus (2005:66) explains that such resources include day care, workshops, or drop-in centres, which are relatively close by.

Respite care services can decrease the carer’s perceived level of burden and provide them with opportunities to pursue other activities, improve their self-esteem, help them to feel secure about possible breakdown of care arrangements, and have a positive influence on family relationships and sleep patterns (Jeon, Chenoweth & McIntosh, 2007:297). Additionally, respite care can delay the institutionalisation of

In this study, the participants were asked to indicate what respite care services are available in the rural communities in which they live, to what extent do they make use of such services and whether they think that respite care will benefit them. Eight participants reported the need for respite care. Service centres for older persons (luncheon clubs), providing day care, were the only available respite care service identified by the participants. Five of the eleven participants reported that the person with Alzheimer’s disease is attending such a service centre during the day. Seven participants mentioned that service centres are available in the communities in which they live. The participants articulated the need for respite care with the following statements:

“It will help me if somebody can look after my wife for a short break. I want to go to my family in Malawi for one week.”

“If it can happen that my father can stay at a service centre the whole day, I will be happy, because then I do not have to worry about him walking around in the street. Or if he can stay with another family member for maybe a week. No longer than that. I will miss him too much.”

“It will help me if my grandfather can go to some other family but they don’t want him.”

The findings suggest that there is an identified need for respite care service among rural dementia caregivers. However, such services are limited to day care centres for the elderly.

- **Sub-theme 5.4: Social work services**

Social work’s ecological systems perspective and training in community-based health care places the profession in a leadership position to meet the challenging health care needs of our ageing society (Behrman, Mancini, Briar-Lawson, Rizzo, Baskind & Valentine, 2006:38). Moreover, social work can foster meaningful
improvements in the quality of life of persons with Alzheimer’s disease, their families and caregivers (Kaplan and Andersen, 2013:174-175). However, literature emphasises the need for social workers to acquire skills and experience in dementia care to deal with the social demands of the older population (Crampton, 2011:314; Kane in Staples and Killian, 2012:332; Kaplan and Berkman, 2011:364).

Manthorpe, Iliffe and Eden (2004:336) refer to various studies that focused on Alzheimer’s related social services provision. Tibbs, for example, made the accusation that the social work profession has neglected the subject. Another study found that 75 percent of the carers of people with dementia who had talked to social workers regarded them as helpful although there were unmet needs for social services among the wider group.

South Africa’s commitment to older people as a primary target group for service delivery is embedded in the adoption of a developmental approach to social welfare that promotes social development by integrating social interventions with economic development (Department of Social Development, 2005 in Lombard & Kruger, 2009:120).

The commitment of government to provide comprehensive social welfare services to older persons, as a vulnerable group, is not a reality in rural communities in Mpumalanga. The results of the current study demonstrate the absence of social work services to older persons with Alzheimer’s, and their caregivers. Despite the fact that all participants indicated that they could benefit from social work services, only two of the eleven participants reported that they have contact with social workers.

The two major role players in providing services to older persons and Alzheimer’s caregivers in Mpumalanga are Alzheimer’s South Africa and Age-in-Action (previously the South African Council for the Aged). Participants were asked whether they are familiar with the services provided by the two non-governmental organisations. Only one participant indicated that she is aware of Alzheimer’s South Africa providing services in the community. None of the participants reported that they are aware of the services provided by Age-in-Action.
No literature could be found to substantiate the absence of social work services to persons with Alzheimer’s disease and their caregivers. The assumption is made that high statutory caseloads, the demands created by HIV/AIDS and poverty, and the shortage of social workers in rural areas have a significant impact on service delivery to this vulnerable group in rural communities.

The ecosystems perspective articulates the interdependence of human problems, situations, and the social conditions in the individual’s life. Social workers can assess the individual’s situation for both strengths and weaknesses in these interactions as well as any distortions. Moreover, social workers can play an important role in improving the quality of life and wellbeing of Alzheimer’s disease sufferers and their caregivers.

- **Sub-theme 5.5: Support groups**
  Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of social isolation (Alzheimer’s Association, 2014:40). Furthermore, support groups create the opportunity to work with the caregivers themselves in order to improve their skills to manage a highly demanding situation and to relieve their emotional distress and maintain their quality of life (Hornillos & Crespo, 2011:156).

The research findings revealed that only three participants attend support groups meetings. The service centres to which they belong offer the support groups. One participant mentioned that there is a support group in her community, but that she does not have the time to attend the meetings, because of her caregiving responsibilities. The remaining participants stated that they are not aware of any support groups existing in their communities. However, they agreed that support groups would be beneficial to share caregiving experiences and learn more about Alzheimer’s disease. Some of the participants had the following to say:

“There are no support groups in our community, but a support group will help to share experiences.”
“There is support groups for caregivers at service centre every month. They learn about Alzheimer’s disease, how to treat patients by centre coordinator.”

“Support groups will help but I don’t have time to go. I cannot leave him (person with Alzheimer’s disease) alone.”

“I attend support group at service centre monthly. It helps me to understand situation of people with Alzheimer’s disease.”

In spite of the potential benefits, Alwin, Öberg and Krevers (2009:240) report that dementia caregivers utilise support services to only a small extent. The low or non-existent use of services by these caregivers may be explained by a number of factors, such as lack of knowledge, cost issues or caregiver unwillingness.

It is clear from the study that support groups can benefit Alzheimer’s caregivers, but that support groups are in most cases, non-existent in rural communities. Support groups, in view of the ecosystems perspective, can assist caregivers to develop new strategies to deal with the challenges facing them.

- **Sub-theme 5.6: Institutional care**

Residential care homes for older persons are widespread in many developed countries. Yet, care homes are rare in developing countries. Governments, as part of their policy to strengthen traditional family care arrangements, have either not encouraged or officially discouraged their development (Prince, Livingston & Katona, 2007:9). This was also found to be the case in black rural communities in Mpumalanga.

Participants were asked whether residential facilities for older persons were available within their communities. None of the participants were aware of any such facilities in their respective communities. The unavailability of institutional care in rural areas of South Africa has been confirmed by a national audit of residential facilities, which was commissioned by the National Department of Social Development in 2010. The audit found that the distribution of such facilities is disproportionate in the wealthier provinces of Gauteng and the Western Cape, with a distinct lack of facilities in poorer
provinces such as Mpumalanga. It was further determined that only five percent of residential facilities in South Africa are in informal or squatter areas, while 16 percent are in rural areas (Department of Social Development, 2010:5).

When asked if they would consider having, the person with Alzheimer’s disease admitted to a residential care facility, almost half of the participants reported that they would consider such an option. However, none of them has submitted an application for admission to a residential care facility. The participants expressed the following views:

“It is very difficult as my culture and religion says we must look after each other. Even if I agree, I will long for her and she will long for me and wonder where I am.”

“Yes, it sometimes comes into my mind that I can take her to an old age home but then it will be good if maybe it could be local so that I can go and visit her.”

“I will not appreciate that. I would feel like I was abandoning him.”

“I think it would be a good thing for him, because he would be safe.”

“My culture does not want it. They told me I must look after my mother in good and in sickness.”

Exhaustion and depression can limit the caregiver’s ability to look after the person with Alzheimer’s disease, and/or serious illness or death can bring on a crisis in the family, resulting in the institutionalisation of the person suffering from the disease (Thomas et al., 2004:128). Likewise, individuals with burdened caregivers are at greater risk of entering a residential care facility (Miller, Rosenheck & Schneider, 2011:383). In contrast, Ogunniyi et al. (2005:259) state that, in developing countries, family cohesion is very strong with notable extended family ties, and home management of persons with Alzheimer’s disease is the favoured pattern. This notion links with the ecosystems perspective that proclaims the functioning of
individuals within the context of the family and community as opposed to institutionalisation.

The key findings of the study suggest that institutional care is as an option for rural persons suffering from Alzheimer’s disease, but that such facilities are lacking in rural communities.

- **Sub-theme 5.7: Religious institutions**

Religion is one part of culture, which dictates outlook, attitudes, behaviour, and impact on Alzheimer’s caregiving (Regan, Bhattacharyya, Kevern & Rana, 2013:2). Research propose that religion plays a significant role in reducing stress and depression associated with Alzheimer’s caregiving (Heo & Koeske, 2011:583) and is a significant predictor of mental wellbeing (Regan, 2014:347). Ten participants in this study reported that they attend weekly religious services in their communities. The participants were asked to explain the role of religion as a coping mechanism in the caregiving situation. The following quotes depict their views:

“The teachings of Islam say you must look after each other. If your partner can’t anymore, you must give back and look after your partner.”

“My religion helps me a lot. My religion say that this (caregiving) is a good thing and what I am doing. God made family to leave the person with me and I feel blessed.”

“The church motivates me about love. Where there is love there is God.”

“The church encourages me with the words from the Bible. I have to care for others.”

“My religions is saying that it is a good thing to do that (caregiving). It is a good thing, because they have even spoken if you have got something like Jesus spoke to Lazarus, that means that I can do anything for myself, that means I am rich and then the other one that is sick or he is old, that means he
The findings demonstrate that religion is a significant motivational force for rural caregivers providing care to persons with Alzheimer's disease. It can be assumed that religion reduces caregiver burden to a certain extent. This finding is consistent with the statement of Regan et al. (2013:9) that internal manifestations of religion are employed when coping with Alzheimer’s caregiving. In terms of the ecosystems perspective, religion is seen as a transactional network and integral part of the cultural makeup in a community.

- **Discussion of theme 5**

Rural dementia caregivers reported that they make use of state clinics and hospitals where professional nurses mostly attend to them. The waiting time at state health care facilities ranges between two and seven hours. The distance to the nearest facility was found to be between 200 metres and 10 kilometres. In general, the participants described their experiences with the public health care system in a negative manner with insufficient information provided by health care professionals about the diagnosis and management of Alzheimer’s disease.

Home-based care services are considered as an effective and affordable community-based service to provide care to persons with Alzheimer’s disease in the community. Despite the importance of home-based care services, only half of the participants are supported by such services.

Respite care can reduce the burden associated with caregiving as it affords caregivers the opportunity to pursue other activities. The study found that service centres for older persons are the only form of respite care available in the rural settings where the study was executed. Almost half of the participants reported that they make use of service centres as a respite care option.

Social work services have the potential to improve the quality of life of persons with Alzheimer’s disease, their families and caregivers. However, social workers need to be skilled to provide in the social demands of the older population. Regardless of
the commitment of government to provide social work services to older persons, the
findings of the study demonstrate a distinct lack of social work services to older
persons with Alzheimer’s disease and their caregivers in black rural communities of
Mpumalanga.

Support groups are deemed valuable for caregivers to share personal feelings,
concerns and experiences, to improve their caregiving skills, and manage the
demands associated with Alzheimer’s caregiving. In spite of their advantages, the
research study found that the vast majority of rural caregivers do not have access to
support groups.

Almost half of the participants in this study reported that they would consider
residential care as a care option for the person with Alzheimer’s disease. Yet,
residential care facilities for older persons are rare in rural communities and none of
the participants indicated that residential care facilities are available in the rural
communities where the study was conducted.

Religion is said to have a positive impact on Alzheimer’s caregiving. Studies show
that religion can improve the mental wellbeing of caregivers. Almost all participants
in this study reported that they actively participate in religious activities and
described religion as a motivating factor for providing care to the person with
Alzheimer’s disease.

3.9 Summary

Five themes were discussed to determine the needs and experiences of caregivers
of persons with Alzheimer’s disease living in black rural communities in
Mpumalanga.

The first theme focused on the rural Alzheimer’s caregiver. The vast majority of
caregivers were female with a mean age of 55 years. All the caregivers had a familial
relationship with the person with Alzheimer’s disease and the mean period of
caregiving was 7.36 years. None of the caregivers received any remuneration for
their caregiving responsibilities. Instead, the caregivers were motivated by cultural

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and family expectations, as well as a sense of duty to provide care to the family member with Alzheimer's disease. It was found that rural caregivers executed their caregiving duties for extended periods of the day, covering a range of caregiving tasks. The intensity of the caregiving tasks increased as the person with the disease become more care dependent. A limited number of caregivers received caregiving training. Nevertheless, caregivers highlighted the need for such training to learn more about Alzheimer’s disease and to assist them to provide quality care to persons suffering from the disease.

The second theme explored the indigenous issues about Alzheimer's disease in rural communities. Although some caregivers felt that the community understands the disease, others emphasised the need for the community to be made aware of the disease. The association between Alzheimer's disease and witchcraft was prevalent in rural communities, ascribing the disease to sorcery and the possession of evil spirits. It became evident that traditional healers, such as sangoma’s and prophets, are highly regarded by rural communities for the diagnoses and treatment of Alzheimer’s disease.

The third theme examined caregivers’ understanding of Alzheimer’s disease. Findings revealed that rural caregivers have limited knowledge of Alzheimer’s disease as a medical condition, its causes, medical treatment and prognosis.

The fourth theme investigated the physical, social and psychological impact of Alzheimer’s caregiving on the rural caregiver. The findings indicated that caregiving is associated with negative health outcomes. Caregivers generally self-assessed their physical health as poor and reported a number of health conditions such as sleep disturbances, diabetes, hypertension, headaches and fatigue. Moreover, findings suggested that caregiving affects the psychological wellbeing of rural caregivers. Caregivers often viewed Alzheimer’s caregiving as a burden, resulting in depression, anxiety, feelings of loneliness and poor quality of life. The study further revealed that caregiving influences the social functioning of caregivers. Rural caregivers experience financial difficulties due to caregiving. Caregivers also reported that they have limited time for themselves, their friends and families, resulting in social isolation and lack of social support. Despite the negative
outcomes associated with Alzheimer’s caregiving, caregivers reported positive experiences such as caregiving being rewarding and affording them the opportunity to give back to their loved ones, families and their community.

The last theme explored the support services available to Alzheimer’s caregivers in the community. The findings indicated that rural caregivers, and their family members with Alzheimer’s disease, are generally dependent on public health care services. Although these services were accessible, most caregivers reported negative experiences with the health care system, with insufficient information provided by health care professionals about the diagnoses and management of Alzheimer’s disease. Home-based care services were available to half of the caregivers. Respite care services were limited to service centres for older persons in rural communities with half of the caregivers utilising this service. The majority of caregivers did not have access to caregiver support groups. The caregivers pointed out the need for social work services. However, social work services were inaccessible to most caregivers. Moreover, caregivers had limited knowledge about social work services available to them. The study further established that no residential care facilities for older persons were available in the rural communities where the study was conducted. However, almost half of the caregivers reported that they would consider having the person with Alzheimer’s disease admitted to such an institution. The vast majority of rural caregivers participate in religious activities and described religion as a motivating factor to provide care to a loved one with Alzheimer’s disease.

The next chapter will focus on the conclusions and recommendations.
CHAPTER 4
SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

The final chapter summarises the research study, to establish if the research goal and objectives were attained and to what extent. Conclusions emanating from the research study are drawn. Lastly, recommendations are made for practice, policy and for further research in line with the themes and sub-themes of the study.

4.2 Summary

The focus of this section is on the objectives, goal and research question of the study and how they were met.

4.2.1 The objectives of the study

The following objectives were pursued to accomplish the goal of the research study:

- To conceptualise Alzheimer’s disease as a condition, including incidence, clinical features, etiology, risk factors, diagnosis, treatment and aspects of caregiving from the ecosystems perspective;
- To identify the current support systems available in black rural communities to caregivers of persons with Alzheimer’s disease;
- To identify the indigenous beliefs about Alzheimer’s disease in black rural communities in Mpumalanga;
- To explore the challenges faced by caregivers of persons with Alzheimer’s disease in black rural communities, and
- To make recommendations for professional support services to caregivers of persons with Alzheimer’s disease in black rural communities.

4.2.1.1 Objective 1: To conceptualise Alzheimer’s disease as a condition

This objective was achieved through an in-depth literature review that was conducted on Alzheimer’s disease and the needs and experiences of caregivers of...
persons with Alzheimer's disease living in black rural communities. The literature review was presented in chapter two of the research report and provided a description of the medical terms and key concepts used in the literature review and the empirical study. The ecosystems perspective as theoretical framework for the study was described. Furthermore, the literature review explored the concepts of dementia, Alzheimer’s disease, caregiving in the context of Alzheimer’s disease and social work and dementia care. Dementia was conceptualised in terms of etiology and epidemiology. Alzheimer’s disease, as the most common cause of dementia, was discussed in terms of incidence, clinical features, etiology, risk factors and stages in the development of the disease, diagnoses and management. Caregiving in the context of Alzheimer’s disease explored caregiving and the Alzheimer’s disease patient, demographic profile of the Alzheimer’s caregiver, the impact of Alzheimer’s disease caregiving, factors influencing the caregiving experience and caregiver interventions. The last section discussed the role of the social work profession in dementia care. The literature review provided the researcher with a comprehensive understanding of Alzheimer’s disease as a neurological condition, caregiving in the context of Alzheimer’s disease and the ecosystems perspective as theoretical framework for the study. This understanding formed the departure point for the empirical study.

4.2.1.2 Objective 2: To identify the current support systems available in black rural communities to caregivers of persons with Alzheimer’s disease

This objective was achieved through the literature review and the empirical study. The literature study focused on community-based caregiver interventions and support systems aimed at reducing caregiver burden. Such interventions and support systems include case management, home-based care, counseling, psycho-educational interventions, support groups, respite care, training of the person with Alzheimer’s disease and psychotherapeutic approaches. Literature showed that caregivers of persons with Alzheimer’s disease rarely seek community support as they are not aware of available services. Therefore, health and social work professionals have the responsibility to link Alzheimer’s disease sufferers and their caregivers with available support services and caregiver interventions in the community. The research data collected from the face-to-face, semi-structured interviews revealed that, although rural caregivers have access to public health care
services, they commonly reported negative experiences with the health care system. Home-based care services were found to be available to some persons with Alzheimer’s disease and their caregivers. Support groups, residential facilities and the utilisation of social work services were found to be lacking in rural communities, with respite care being limited to service centres for older persons. Religion and religious institutions were found to be significant support systems for rural caregivers.

4.2.1.3 Objective 3: To identify the indigenous beliefs about Alzheimer’s disease in black rural communities in Mpumalanga
This objective was attained through the literature review and the empirical study conducted. Literature indicates that Alzheimer’s disease, in South Africa, is often ascribed to witchcraft or evil spirits. This prevents persons with Alzheimer’s disease and their caregivers from getting the necessary medical attention and social support. The data collected revealed that community members and caregivers offer various explanations about the causes of Alzheimer’s disease. Findings suggested that the association between Alzheimer’s disease and witchcraft, evil spirits and sorcery is prevalent in rural communities. This belief results in the treatment of persons with Alzheimer’s disease by traditional healers. It also results in persons with Alzheimer’s disease being stigmatised in rural communities leading to poor social support which further impacts on caregiver burden.

4.2.1.4 Objective 4: To explore the challenges faced by caregivers of persons with Alzheimer’s disease in black rural communities
This objective was achieved by means of the literature study and the empirical research. The literature study explored the physical, psychological and social impact of Alzheimer’s disease on the rural caregiver population and the factors influencing the impact of caregiving. It was found that caregivers face numerous challenges resulting in caregiver burden. The results yielded by the empirical study found that Alzheimer’s caregivers very often have limited understanding about Alzheimer’s disease as a medical condition. In addition, the lack of support structures in rural communities was found to be a significant challenge for caregivers. The empirical findings showed that Alzheimer’s caregiving negatively influenced the physical, psychological and social wellbeing of rural caregivers. Despite the negative impact
of caregiving, rural caregivers reported a number of positive aspects associated with Alzheimer’s caregiving.

4.2.1.5 Objective 5: To make recommendations for professional support services to caregivers of persons with Alzheimer’s disease in black rural communities

This objective was achieved and is discussed at the end of the current chapter. Recommendations for practice, policy and future research are based on the research findings and conclusions drawn from the study regarding the needs and experiences of Alzheimer’s caregivers living in black rural communities.

4.2.2 Goal of the study

The goal of the study was to explore the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga. This goal was achieved by means of the following:

Achievement of the above objectives led to the goal being met. The literature review chapter explored the ecosystems perspective as the conceptual framework for understanding the relationship between caregivers and their social environment; the needs, challenges and strengths of individuals and their families; and the resources in the environment. The concept of dementia was conceptualised, focusing on etiology and incidence. Alzheimer’s disease, as the most common cause of dementia, was explored in terms of incidence, clinical features, etiology and risk factors. Staging models in the development of Alzheimer’s disease and diagnosis were described with specific reference to the new diagnostic criteria of Alzheimer’s disease contained in the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* and recent developments in the use of biomarkers in diagnosing Alzheimer’s disease. The management of Alzheimer’s disease in terms of pharmacological and non-pharmacological treatment was scrutinised. The concept of caregiving in the context was Alzheimer’s disease was discussed with specific reference to caregiving tasks, demographic profile of the Alzheimer’s caregiver, the impact of Alzheimer’s caregiving and factors influencing the caregiving experience. The final section of the literature review conceptualised social work and dementia
care. Specific emphasis was placed on the role of the social worker specialising in gerontology and providing services to older persons, their families and caregivers.

The empirical research generated the following themes: the Alzheimer’s disease caregiver, indigenous issues about Alzheimer’s disease, caregivers’ understanding of Alzheimer’s disease, the impact of Alzheimer’s disease on the caregiver, and support services in the community. Each of these themes were divided into sub-themes to explore the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga. The theme of the Alzheimer’s disease caregiver had four sub-themes including caregiver remuneration, hours per day and week providing care to persons with Alzheimer’s disease, caregiving tasks provided and caregiver training received. The theme of indigenous issues about Alzheimer’s disease was divided into three sub-themes including community knowledge of Alzheimer’s disease and attitudes, indigenous beliefs in the community about Alzheimer’s disease and traditional treatment practices related to Alzheimer’s disease. The theme of caregivers’ understanding of Alzheimer’s disease had four sub-themes, which included Alzheimer’s disease as medical condition, causes of Alzheimer’s disease, symptoms of Alzheimer’s disease and medical treatment and prognosis of Alzheimer’s disease. The theme of the impact of Alzheimer’s disease was divided into four sub-themes, namely physical impact of caregiving, psychological impact of caregiving, social impact of caregiving and positive aspects of caregiving. The last theme exploring support systems in the community had seven sub-themes, including health care services, home-based care services, respite care, social work services, support groups, institutional care and religious institutions.

4.2.3 Research question

In the context of this study, the following research question was asked:

*What are the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga?*

The data collected from the in-depth interviews with the participants revealed themes and sub-themes relating to the needs and experiences of caregivers of persons with
Alzheimer’s disease living in black rural communities in Mpumalanga. As the research was qualitative in nature, descriptive data was obtained. These descriptive needs and experiences of Alzheimer’s caregivers were discussed in chapter three.

The following themes reflect the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga:

Theme 1: The Alzheimer’s disease caregiver

Theme 2: Indigenous issues about Alzheimer’s disease

Theme 3: Caregivers’ understanding of Alzheimer’s disease

Theme 4: The impact of Alzheimer’s disease on the caregiver

Theme 5: Support services in the community

These themes, together with their sub-themes, were discussed comprehensively in the previous chapter.

Table 4.1: Themes and sub-themes of research

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<th>THEMES</th>
<th>SUB-THEMES</th>
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| The Alzheimer’s disease caregiver | • Caregiver remuneration  
• Hours per day and week providing care  
• Caregiving tasks  
• Caregiver training |
| Indigenous issues about Alzheimer’s disease | • Community knowledge of Alzheimer’s disease and attitudes  
• Indigenous beliefs  
• Traditional treatment practices |
| Caregivers’ understanding of Alzheimer’s disease | • Alzheimer’s disease as a medical condition  
• Causes  
• Symptoms  
• Medical treatment and prognosis |
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4.3 Conclusions

The conclusions were drawn from the literature study presented in chapter two and the key findings of the empirical study contained in chapter three.

4.3.1 Conclusions from literature study

The ecosystems perspective, as theoretical foundation for this study, proved to be appropriate as it helped the researcher to understand the relationship between caregivers and their social environment, cultural context and their interactions with support systems in the community. It highlighted that humans do not develop without the influence of their personal ecosystem and the larger ecosystem, of which they are part. Furthermore, it was appropriate for caregiving in rural settings as it contributes to empowerment of the individual within the health care system, as it takes into account the multiple and complex transactions that take place between individuals, within their families and environments. Importantly, the perspective allowed for the assessment of strengths and weaknesses in these interactions. The ecosystems perspective therefore enabled the researcher to identify the needs and experiences of participants providing care to Alzheimer’s sufferers in rural communities. The ecosystems perspective has become the most widely used approach for understanding the relationship between individuals and their social environment.
The literature study showed that the global population of older persons is rapidly growing, with an increase in associated chronic diseases such as Alzheimer's disease. It is estimated that 25 to 30 million people worldwide are suffering from Alzheimer's disease. This number is expected to triple by 2040. The increase in age related conditions is becoming a serious public health problem in many countries with informal caregivers assuming the immense responsibility for providing informal home care to persons with Alzheimer's disease. Literature emphasised that Alzheimer's caregiving is associated with burden of care and impacts the physical, psychological and social wellbeing of caregivers. Alzheimer’s caregivers are often not skilled or equipped for this enormous task with support services lacking in many communities. This situation is aggravated by a poor understanding and knowledge of Alzheimer's disease among communities, caregivers, social workers and health care professionals. Stigma was indicated in literature as having a significant effect on caregivers. In some African cultures, Alzheimer's disease is associated with witchcraft or the person suffering from the disease is seen as being possessed by evil spirits. For this reason, many persons living in rural communities rely on traditional healers for the diagnosis and treatment of Alzheimer's disease. Literature suggested a number of caregiver interventions to improve the health or wellbeing of Alzheimer’s caregivers and emphasised the importance of social work services to help caregivers cope with the demands of caregiving.

4.3.2 Conclusions from research methodology

The qualitative approach, using the case study design and specifically collective case studies proved to be the appropriate approach and research design for this study. The information gathered was personal and rich in nature which gave meaning to the needs and experiences of Alzheimer's caregivers in black rural communities in Mpumalanga. The collective case study design was appropriate as the researcher was able to broaden his understanding of the needs and experiences of all the participants.

The use of in-depth face-to-face interviews and the semi-structured interview schedule enabled the researcher to obtain first-hand information in the form of words from the participants. It further allowed some flexibility to explore certain topics further during the interviews. It can therefore be concluded that the face-to-face
interviews and semi-structured interview schedule, as methods of data collection used in interviewing the participants and the recordings worked effectively in collecting data. The transcriptions helped the researcher to become familiar with the contents of each interview and understand the needs and experiences of the participants, as well as to identify themes and sub themes from the data. The researcher can therefore recommend these methods to future researchers who are planning to explore the needs and experiences of Alzheimer’s caregivers.

The linear steps of data analysis, as proposed by Creswell, Marshall and Rossman (in Schurink et al., 2011:404-419), were used during the research process. The steps in the data analysis process included planning for the recording of data; data collection and preliminary analysis; managing data and reading; generating categories, themes and patterns and coding data; testing emergent understandings and searching for alternative explanations and presenting the data in the form of a mini-dissertation. This method of qualitative data analysis enabled the researcher to convert raw data into meaningful information. Credibility, transferability, dependability and conformability were considered to establish trustworthiness of data. The researcher used clarification during the interviews to confirm findings with participants to establish the trustworthiness of data and to ensure that findings reflect the meanings described by the participants.

4.3.3 Conclusions from research findings
The researcher is of the opinion that the findings of this study cannot be generalised, but that the findings could be transferrable to a similar setting in Mpumalanga with a similar population.

The following conclusions are made according to the key findings in each theme:

4.3.3.1 Theme 1: The Alzheimer’s disease caregiver
The research showed that providing care to a person with Alzheimer’s disease is an immense task. Caregiving in rural communities are generally provided by females, without any remuneration and, in many instances, without training received.
• **Sub-theme 1.1: Caregiver remuneration**
None of the participants in the study reported that they receive any remuneration for providing care to the person with Alzheimer’s disease. The vast majority of the participants reported being dependent on social grants as their only source of income. These grants include old age pensions, disability grants and child support grants received from government. Low household incomes and limited resources can result in increased caregiver risk for negative outcomes. Cultural aspects and a sense of family responsibility were found to be motivating factors for providing care to loved ones with Alzheimer’s disease.

• **Sub-theme 1.2: Hours per day and week providing care**
Alzheimer’s disease is a progressive and chronic disease, and therefore it is inevitable that the affected person will become increasingly care dependent. This care dependency will result in increased caregiving demands. Despite the fact that participants could not accurately specify the exact number of hours providing care to the person with Alzheimer’s disease, the majority indicated that caregiving is a full-time responsibility. Most of the participants reported that they provide care for extended hours per day, as the person with Alzheimer’s disease needs constant supervision and assistance with most activities of daily living. Only one participant indicated that she is assisted by other family members during the day. Some of the Alzheimer’s sufferers were found to attend service centres for older persons during the day which provided caregivers with some relief.

• **Theme 1.3: Caregiving tasks**
Caregiving typically involves a significant expenditure of time and energy over potentially long periods of time. Caregiving provided to persons with Alzheimer’s disease are linked to deterioration in cognition, function and behaviour throughout the various stages of the disease and include support with all activities of daily living. It often involves tasks that may be unpleasant, and uncomfortable and which are psychologically stressful and physically exhausting.

The study showed that during the early stages of the disease, caregiving involved the provision of emotional support to the person with Alzheimer’s disease, assistance with instrumental activities such as household chores, managing of
finances and shopping, reminding the Alzheimer’s sufferer of certain events and
tasks and providing assistance with taking medication and following treatment
recommendations.

During the middle stage of the disease, participants reported an increased and
constant need for supervision. Caregiving included assistance with communication
strategies, help with personal care and hygiene, help with transportation, increased
help with activities of daily living such as food preparation, feeding, appropriate
dressing, bathing and toileting, and preventing the person with the disease from
wandering and getting lost. In the final stages of Alzheimer’s disease, care, support
and supervision became more constant where caregivers had to provide full physical
care and deal with behavioural problems of the person suffering from the disease.

- **Sub-theme 1.4: Caregiver training**
  Caregivers often have inadequate knowledge and feel unprepared to provide proper
care and are therefore overwhelmed by the enormous caregiving demands. The
study found that only a few of the participants received some form of caregiver
training. The training was presented by Alzheimer’s South Africa in Mpumalanga.
All participants reported that caregiver training would benefit them to provide better
care to their relatives with Alzheimer’s disease. The participants further pointed out
that such training would benefit to understand Alzheimer’s disease, provide them
with practical information about caregiving and help them to cope with the caregiving
situation. It is the researcher’s opinion that having knowledge about Alzheimer’s
caregiving can result in positive caregiving outcomes. Caregiver training can
improve the quality of care, reduce the stress placed on caregivers and improve their
wellbeing and quality of life.

**4.3.3.2 Theme 2: Indigenous issues about Alzheimer’s disease**
The research revealed that participants had diverse views related to the knowledge,
understanding and attitudes of the community about Alzheimer’s disease and that
lay conceptions about the disease were influenced by the cultural perspective from
which they are being viewed. The findings further showed that the use of traditional
medicine was prominent in rural communities for the treatment of Alzheimer’s
disease.
• **Sub-theme 2.1: Community knowledge of Alzheimer’s disease and attitudes**

The literature review showed that people have varying knowledge about Alzheimer’s disease. Misconceptions and ignorance about the disease negatively affect caregivers and persons with Alzheimer’s disease which often result in stigmatisation and social isolation.

It emerged in the research findings that participants experienced the understanding and attitude of rural communities about Alzheimer’s disease in different ways. Some participants reported that the community in general did not understand the disease, did not care about the person with Alzheimer’s disease and attributed the condition to witchcraft. On the other hand, some participants indicated that the community understood the disease and that community members were supportive towards the person with Alzheimer’s disease. It was found that close-by neighbours and community members known to the participant and Alzheimer’s sufferer were more enlightened about the disease. They also had less negative attitudes towards persons with Alzheimer’s disease and were more willing to assist when needed. Almost all the participants expressed the need for awareness campaigns to enhance the knowledge of the community about Alzheimer’s disease. The researcher is of the opinion that knowledge about the disease among rural community members will result in less negative attitudes towards persons with Alzheimer’s disease and their caregivers and reduce the level of social isolation experienced by caregivers.

• **Sub-theme 2.2: Indigenous beliefs**

In African rural communities, Alzheimer’s disease as an illness is highly stigmatised and shrouded in myth. Communities generally see older persons who display demented behaviour as having been placed under evil spell, either by their ancestors, or by a witch. Such beliefs are found to be rooted in culture and result in alienation of persons suffering from the disease. Also, it prevents persons with Alzheimer’s disease and their caregivers from getting the necessary medical attention and social support. The study showed that most rural community members associated Alzheimer’s disease with witchcraft, sorcery and spiritual possession. More than half of the participants, in their view, indicated that Alzheimer’s disease was caused by witchcraft, spiritual possession, ancestral influences or demons.
• **Sub-theme 2.3: Traditional treatment practices**

Traditional healing is a common practice in South African rural communities and is very often the first choice of treatment for many South Africans who suffer from psychiatric illnesses such as Alzheimer’s disease. Literature revealed that eight out of every ten black South Africans rely on traditional medicine alone, or in combination with Western medicine.

The study showed that more than half of the persons with Alzheimer’s disease have been treated by traditional healers such as sangoma’s and prophets. Various treatment methods were reported such as traditional medicine and communication with ancestors. In spite of the fact that many South Africans rely on traditional healing for the treatment of Alzheimer’s disease, participants did not report that traditional healing was effective for the treatment of the disease.

**4.3.3.3 Theme 3: Caregivers’ understanding of Alzheimer’s disease**

The literature study revealed that caregivers of persons with Alzheimer’s disease often have poor knowledge about the disease which can adversely affect appropriate help seeking. Having sufficient knowledge of the disease will benefit caregivers to cope with the caregiving demands and the deterioration in cognitive and physical function experienced by persons with Alzheimer’s disease.

• **Sub-theme 3.1: Alzheimer’s disease as a medical condition**

A better understanding of Alzheimer’s disease is a critical step towards improving the care of persons with this condition. This knowledge will help to give caregivers more realistic expectations about what they will confront as the disease progresses and help them to cope adequately as caregivers. Yet, analysis of data has shown that rural participants, in general, had insufficient knowledge and a poor understanding of Alzheimer’s disease as medical condition. The participants offered various explanations about the condition of the person suffering from the disease. About half of the participants indicated that the person suffered from some form of mental illness. The other half had other explanations for the disease such as that the person was stressed, longed for a deceased family member or that the person thought too much.
• **Sub-theme 3.2: Causes of Alzheimer’s disease**

Many caregivers do not understand the causes of the illness of the person to whom they provide care. Lay explanations of Alzheimer’s disease are often tied to ethnicity and/or culture. The findings indicated that rural participants had limited knowledge about the medical causes of the disease. Only a small number of participants linked Alzheimer’s disease with advanced age or brain dysfunction. The majority of participants offered other explanations as possible causes of the disease. These explanations included the loss of a family member, witchcraft, stress and family problems. An understanding of Alzheimer’s disease, as a degenerative brain disorder, can help caregivers to seek appropriate medical care for the person with the disease and reduce stigma associated with the disease.

• **Sub-theme 3.3: Symptoms of Alzheimer’s disease**

There are four main symptom categories of Alzheimer’s disease namely, memory impairment, behavioural and personality changes, intellectual impairment and physical changes. The study found that participants, based on their caregiving experience, were able to identify the symptoms of Alzheimer’s disease. Symptoms of memory impairment included the inability to recall names, inability to recognise familiar persons, memory loss and misplacing items. Behavioural and personality changes included aggression, undressing, wandering, getting lost, suspicious behaviour, inappropriate dressing, poor hygiene and refusing to bath, sleep disturbances, hallucinations and delusions. Intellectual impairment included the inability to communicate, inability to perform motor functions and the inability to perform complex tasks. Physical changes included frailty and incontinence. This finding correlates with the literature study which revealed that the caregiver is very often the first person to observe the symptoms of Alzheimer’s disease. The correct understanding of Alzheimer’s disease symptoms can facilitate the early detection of the disease, resulting in improved benefits of treatment.

• **Sub-theme 3.4: Medical treatment and prognosis of Alzheimer’s disease**

Literature emphasised that there is no cure for Alzheimer’s disease. Still, current medicines can control the psychotic and behavioural symptoms of the disease. It emerged from the research findings that participants had limited understanding of the poor prognosis and clinical course of Alzheimer’s disease. Less than a third of
the participants were of the opinion that medical treatment could benefit the person with Alzheimer’s disease. More than half of the participants indicated that the disease is curable. It is the opinion of the researcher that this lack of knowledge about the medical treatment and prognosis of Alzheimer’s disease could deny persons with Alzheimer’s disease of appropriate medical treatment. Caregivers can play an important role in the diagnosis and treatment of persons with Alzheimer’s disease. They are often the first to observe changes in behaviour and functioning and can therefore provide useful information to health care professionals for the clinical assessment of the person with Alzheimer’s disease. Also, treatments are typically implemented by the caregiver.

4.3.3.4 Theme 4: The impact of Alzheimer’s disease on the caregiver
Although caregivers of persons with Alzheimer’s disease perform an important service for society, and their relatives, they do so at considerable cost to their own physical, psychological and social wellbeing.

- **Sub-theme 4.1: Physical impact of caregiving**
  There is a wealth of literature documenting the negative physical health outcomes associated with caregiving. These health outcomes include general decline in physical health, cardiovascular disease, reduced immune function, hypertension and even early death. The empirical findings of the study revealed that almost all of the participants self-assessed their health as poor, while the vast majority of participants indicated that caregiving negatively affected their health status. Most of the participants reported that they visited a health clinic at least once every month. The most frequent self-reported health conditions included hypertension, generalised body aches, headaches, fatigue, sleep disturbances, diabetes and HIV and AIDS. These negative health outcomes are aggravated by the limited community support services available to caregivers and highlight the need for effective coping strategies.

- **Sub-theme 4.2: Psychological impact of caregiving**
  Caregiving significantly affects the psychological health of Alzheimer’s disease caregivers. Caregivers often lack the skills to manage the behaviours of persons with Alzheimer’s disease and their own stress which can lead to adverse psychological consequences. The findings of the study are consistent with literature
and found that participants often experienced feelings of depression and loneliness and viewed caregiving as stressful. These psychological symptoms associated with caregiving were found to be a significant cause of caregiver burden and compromised the quality of life of participants. The researcher argues that the psychological impact of caregiving can be lessened by caregiver intervention strategies. The social worker specialising in health care or gerontology has a significant role to play in the design and implementation of such intervention strategies.

- **Sub-theme 4.3: Social impact of caregiving**
  Caregiving in the context of Alzheimer’s disease often has a negative influence on the social functioning and wellbeing of caregivers. Negative social outcomes include role conflict and role-overload, family dysfunction, restricted social activities, financial burden, employment issues and the lack of social and emotional support. In addition, black rural caregivers are exposed to chronic stressors such as unemployment and poverty.

  The study revealed that the majority of participants reported limited time for themselves, their families and friends which resulted in feelings of social isolation and perceived lack of social support. This role overload was further heightened by the fact that many participants had to look after children and other family members in their care. Most of the participants reported that they experienced financial difficulties as a result of caregiving. Social grants were found to be the only income for most of the participants, whereas none of the participants reported receiving any remuneration for their caregiving responsibilities. Some participants indicated that they were unable to seek employment as a result of the fulltime nature of caregiving. A third of the married participants reported that caregiving had an influence on their marriage. It was found that participants generally experienced a lack of social support. The researcher is of the opinion that social support and social work intervention could positively influence the overall functioning of rural caregivers.

- **Sub-theme 4.4: Positive aspects of caregiving**
  Caregiving is both a burden and a positive experience for Alzheimer's caregivers. Positive aspects of caregiving include both rewards and satisfaction derived from the
caregiving relationship. Despite the suffering, most participants found positive aspects and meaning in the caregiving process. Participants described the caregiving experience as rewarding as it afforded them the opportunity to give back to the community, their families and the person suffering from Alzheimer’s disease. Participants reported love, duty and moral obligation as motivating factors for caregiving. Finding meaning in caregiving may mediate the relationship between burden and mental health and serve as motivation to provide care.

4.3.3.5 Theme 5: Support services in the community
Most persons with Alzheimer’s disease are cared for in the community. Support services in the community can complement the care provided by Alzheimer’s caregivers and empower caregivers with knowledge and skills and provide them with much needed emotional support. In spite of the benefits of community support services, it was found that the overall use of such services was quite low. The low use of support services may be attributed to the limited availability of these services in rural settings, the lack of caregiver awareness of these services in rural areas, and/or difficulty in service access.

- **Sub-theme 5.1: Health care services**
Health care professionals can help caregivers to reduce the risk of adverse caregiving outcomes by explaining the Alzheimer’s disease process, advising caregivers how to manage disease symptoms and linking them with support services in the community. In spite of the important role that health care professionals can fulfil, literature proposed that the elderly, and particularly those with dementia, are not a health care priority in South Africa and that caregivers get little help from health care professionals in managing their tasks and the emotional demands of caregiving. This can probably be ascribed to the fact that the public health care sector in South Africa is overwhelmed by the demands of other prevailing medical conditions such as HIV and AIDS, tuberculosis and malaria, to mention a few.

It surfaced in the study that all the participants were dependent on health care services provided by government, and in most instances, services provided by local clinics where they were most frequently attended to by professional nurses. Although such facilities were found to be accessible to all participants, long waiting
times were reported. Half of the participants made use of public transport to access health care services which resulted in further financial implications. The other half reported that they walked to clinics or hospitals. In general, the participants reported negative experiences with the public health care system. Health care professionals were reported to have negative attitudes towards the persons with Alzheimer’s disease, and their caregivers, and provided them with insufficient knowledge about the diagnosis and management of Alzheimer’s disease. The negative attitudes of health care professionals, and the insufficient knowledge provided about Alzheimer’s disease, can result in negative help seeking behaviours which deny persons suffering from the disease, and their caregivers, from receiving the necessary medical care. Health care professionals should provide proactive caregiver support and monitor their health and wellbeing, in addition to caring for the person with Alzheimer’s disease. Also, health care professionals should provide caregivers with guidelines to observe, monitor and manage the persons with the disease.

- **Sub-theme 5.2: Home-based care services**
  Persons with Alzheimer’s disease are in need of long-term care and assistance with their activities of daily living rather than skilled 24-hour medical care. Such care is provided by home-based care services. The aim of home-based care is to provide effective and affordable care and support to ill persons in their own natural environment and includes physical, emotional, spiritual and palliative care provided by formal and informal caregivers. The study found that about half of the participants made use of home-based care services whereas the other participants indicated that they would benefit from such services. Home-based care services are regarded by the researcher as a valuable support service in the community, especially in the absence of residential care facilities for older persons.

- **Sub-theme 5.3: Respite care**
  Respite care is one of few community-based services that has a primary focus on supporting caregivers. Such services commonly include day care, workshops, drop-in centres or periodic institutionalisation. Respite care is an arrangement to allow relief caregivers or “time-out” from their care commitments, which may be provided on a regular basis or in emergencies. The study indicated that respite care services were limited to service centres for older persons (luncheon clubs) which provided
day care to persons with Alzheimer’s disease. Almost half of the participants reported that service centres were utilised by the persons with Alzheimer’s disease as a form of respite care. Regardless of the fact that the majority of participants articulated that they would benefit from such services, service centres were not reported to be available in all the communities where the study was conducted. The availability of respite care can have a number of benefits for caregivers such as allowing time for rest, improvement in family relationships and sleep patterns, freedom to pursue other activities and allowing time to rest and relax.

- **Sub-theme 5.4: Social work services**
Alzheimer’s disease can place unbearable demands on caregivers because of the high levels of physical and emotional care and support and changes in family roles and responsibilities. These demands dictate the intervention of the social worker to enhance the functioning and wellbeing of persons with Alzheimer’s disease and their caregivers. Despite the pivotal role of social workers in Alzheimer’s care, literature illustrated that social work services are very often ineffective in meeting the needs of caregivers. The results yielded by the study showed that a significantly small proportion of participants had access to social work services. However, all participants expressed the need for such services. Moreover, it was found that participants were generally unaware of the existence and services provided by the two major organisations providing care to older persons in Mpumalanga, namely Alzheimer’s South Africa and Age-in-Action. The researcher argues that limited awareness of social work services in rural communities negatively influences the utilisation of such services.

- **Sub-theme 5.5: Support groups**
Support groups are regarded as valuable community support structures affording Alzheimer’s caregivers the opportunity to share personal feelings and concerns, overcome feelings of social isolation, improve their caregiving skills and learn about resources available in the community. Support groups may further provide a coping mechanism to deal with caregiver stressors. The study however found that most participants were not aware of support groups functioning in their communities. Only three of the eleven participants attended support groups offered by the service centres to which they belonged. The majority of participants agreed that support
groups would be beneficial to share caregiving experiences and learn more about Alzheimer's disease.

- **Sub-theme 5.6: Institutional care**
  Residential care facilities for older persons are a rare commodity in rural communities and are often not accessible to older persons living in these communities. This situation is further compounded by the shift in government policies from institutional care to community-based care in an effort to strengthen traditional family care arrangements. The study yielded similar results. Participants reported that residential care facilities for older persons were not available in their rural communities. However, almost half of the participants indicated that they would consider residential care as a care option for the persons with Alzheimer's disease. The other half of the participants reported that institutional care was not an option as they felt obliged to provide care to their family members suffering from the disease.

  In the view of the researcher, government should review its policy on residential care facilities for older persons, as institutional care is often the most appropriate care option for persons with Alzheimer’s disease, for several reasons. Family members or caregivers may not be able to provide the 24-hour care that is necessary. Problem behaviours such as wandering and getting lost may make the home environment unsafe and persons with the disease may require special care that cannot be provided in the home.

- **Sub-theme 5.7: Religious institutions**
  Religion was indicated in literature as significant in reducing stress and depression associated with caregiving as it dictates outlook, attitudes, behaviour and impacts on Alzheimer’s caregiving. The study indicated that virtually all the rural participants viewed religion as an important aspect of their lives. The participants reported that they attended weekly religious services in their communities. Religion was found to be a motivational factor for providing care to family members with Alzheimer’s disease as well as a coping mechanism to deal with the demands of caregiving. Religion was further found to reduce caregiver burden to a certain extent and improved the wellbeing of participants.
4.4 Recommendations

4.4.1 Recommendations for practice

It is in the context of the conclusions discussed above that recommendations are made to address the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities. The recommendations are made according to each theme of the study.

4.4.1.1 Theme 1: The Alzheimer’s disease caregiver

- **Sub-theme 1.1: Caregiver remuneration**

  Rural caregivers of persons with Alzheimer’s disease are in most instances dependent on government grants such as old age pensions, disability grants and/or child support grants as their only source of income. The nature and extent of their caregiving responsibilities prevent caregivers from seeking or entering full-time employment. This results in caregivers living in poverty. Government should review its policy on care dependency grants to not only support families with disabled children, but also those individuals with conditions such as Alzheimer’s disease who are in need of full-time care and support. In addition, caregivers should be engaged in poverty alleviation and income-generating programmes to provide in their basic needs. It is recommended that material assistance be provided to caregivers living in poverty.

- **Sub-theme 1.2: Hours per day and week providing care**

  It is evident that providing care to a person with Alzheimer’s disease is a mammoth task with caregivers receiving limited support from other family and community members. Very often, Alzheimer’s caregivers have the added responsibility of providing care to children and other family members. To reduce the burden and negative outcomes associated with caregiving, respite care such as day care facilities for older persons, should be available in all communities. Furthermore, the availability of home-based care services, subsidised by government, should be increased to provide support services to all persons with Alzheimer’s disease, and their caregivers, within the community.
Theme 1.3: Caregiving tasks
As Alzheimer’s disease progresses, the affected persons become increasingly care dependent. This increase in care dependency is associated with heightened caregiving demands which negatively influence the wellbeing of caregivers. As already discussed in Theme 1.2, home-based care services, if available, could assist caregivers with managing the caregiving demands.

Theme 1.4: Caregiving training
Empowering rural caregivers with knowledge and skills to provide care to persons with Alzheimer’s disease and to cope with caregiving demands can improve their wellbeing and quality of life. The researcher is of the opinion that caregiver training can enhance problem-solving skills and reduce stress and depression associated with burden of care. Such training can be provided by the Department of Social Development, Alzheimer’s South Africa, Age-in-Action, religious institutions and home-based care organisations.

4.4.1.2 Theme 2: Indigenous issues about Alzheimer’s disease

Theme 2.1: Community knowledge of Alzheimer’s disease and attitudes
There is a need for awareness campaigns to educate community members about Alzheimer’s disease as a medical condition, its course, treatment and prognosis. Community events and community radio stations, for example, can be used as opportunities to create awareness about the disease. It is believed that such awareness campaigns, addressing the myths and misconceptions about the disease, will positively influence the attitudes of community members towards persons with Alzheimer’s disease and their caregivers. Community knowledge about the disease will, in addition, elicit community support and reduce the stigmatisation and social isolation experienced by persons suffering from Alzheimer’s disease and their caregivers.

Sub-theme 2.2: Indigenous beliefs
The significance of cultural perspectives concerning mental illness in rural communities should not be underestimated. It is therefore essential for social work and health care professionals working in rural areas to have knowledge about indigenous beliefs in the community and an understanding of their health belief
context. In addition, these professionals should respect the cultural perspectives of rural community members. Nevertheless, caregivers and community members can be challenged to broaden their views about Alzheimer’s disease as a medical condition.

- **Sub-theme 2.3: Traditional treatment practices**
  Professionals practising in rural communities should acknowledge the important role of traditional healing in the provision of rural health care services. Despite the fact that persons with Alzheimer’s disease may utilise Western treatment options, they are often referred to traditional healers for diagnosis and treatment. It is recommended that extensive education be provided to traditional and faith healers about the disease. For traditional and faith healers to feel involved, policy makers should consult with them as policy implementers when developing intervention strategies for the management of Alzheimer’s disease at community level. Moreover, traditional and faith healers should be included in community awareness campaigns about Alzheimer’s disease as they have the potential to influence rural community members about health issues. Also, Alzheimer’s suffers and their caregivers should be encouraged to stop relying solely on traditional medicines for healing, as there is no cure for the disease and to access health care services.

4.4.1.3 Theme 3: Caregivers’ understanding of Alzheimer’s disease

- **Sub-theme 3.1: Alzheimer’s disease as a medical condition**
  Indigenous beliefs about Alzheimer’s disease are common in rural communities and caregivers often display poor knowledge of the disease as a medical condition. Sub-theme 2.1 discussed the importance of educating community members about Alzheimer’s disease as medical condition. Likewise, the importance of educating Alzheimer’s caregivers cannot be overemphasised. Social workers and health care professionals can provide Alzheimer’s education to caregivers. Informed caregivers will be more likely to engage the Alzheimer’s sufferer in medical regimens for the management of the disease. It is further argued that informed caregivers will experience less negative caregiving outcomes based on their understanding of the disease.
• **Sub-theme 3.2: Causes of Alzheimer's disease**  
Caregivers commonly have limited insight into the causes of Alzheimer's disease. Although the exact causes are unknown, the researcher is of the opinion that educating caregivers about the risk factors of the disease, such as advanced age, diabetes, hypertension, and head trauma will enhance their understanding of Alzheimer's as progressive and degenerative brain disorder. It will furthermore enhance medical help-seeking behaviour and reduce the stigma associated with the disease. Psycho-educational support groups can be utilised to provide caregiver education. It is further recommended that health care professionals should be empowered to render health information and health promotion services to Alzheimer’s caregivers.

• **Sub-theme 3.3: Symptoms of Alzheimer's disease**  
The symptoms displayed by Alzheimer’s sufferers are often disturbing to caregivers resulting in caregiver stress. Such symptoms include wandering, aggression, violent behaviour and the inability to communicate. The intensity of the symptoms increases as the disease progresses. Caregivers frequently have limited knowledge and skills to manage these symptoms. It is important for caregivers to be educated about the symptoms of the disease and the management thereof. Symptom education will also help caregivers to anticipate what can be expected as the disease progresses. Importantly, caregivers should be helped to recognise the impact of the symptoms displayed by the care recipient on their own physical and psychological wellbeing, with counselling provided where necessary. Lastly, caregivers should be made aware of the pharmacological and other interventions available to manage the symptoms of Alzheimer’s disease.

• **Sub-theme 3.4: Medical treatment and prognosis of Alzheimer's disease**  
There is no cure for Alzheimer’s disease. However, disease progression and symptomatology can be managed with medication. Hence, it is important for health care professionals to educate caregivers about the treatment options available for the person suffering from the disease.
4.4.1.4 Theme 4: The impact of Alzheimer’s disease on the caregiver

- **Sub-theme 4.1: Physical impact of caregiving**
  The adverse health outcomes of Alzheimer’s caregiving have been emphasised in this study, hence the need for health promotion strategies directed at caregivers. Health care professionals should not only be trained to provide in the health care needs of persons with Alzheimer’s disease, but also their caregivers. Identifying and managing the symptoms of caregiver burden can result in more favourable health outcomes. Health education strategies should be employed to inform caregivers of health behaviours that can affect their physical wellbeing and encourage them to make use of appropriate health care services available in the community. Likewise, social workers should educate caregivers about the importance and benefits of proper health care to minimise the negative health outcomes associated with Alzheimer’s caregiving.

- **Sub-theme 4.2: Psychological impact of caregiving**
  Alzheimer’s caregiving, in most instances, compromises the psychological wellbeing of caregivers. Caregivers often experience depression, increased stress levels and feelings of loneliness. Caregiver interventions should teach caregivers behaviour management skills targeting the care recipients’ problematic behaviour and deficits such as the inability to communicate, which are major caregiver stressors. Also, intervention strategies should focus on caregiver problem-solving skills targeting health behaviours. It is however important for caregiver interventions to be culturally competent to acknowledge racial, ethnic and cultural differences in the stress associated with Alzheimer’s caregiving.

- **Sub-theme 4.3: Social impact of caregiving**
  Alzheimer’s caregivers often experience feelings of social isolation at times when their need for social support is the greatest. Intervention strategies should therefore increase the quality and quantity of social contact to improve caregiver wellbeing. Such interventions can include caregiver support groups, social support and social skills. Casework with Alzheimer’s caregivers should focus on developing skills to manage role conflict and rearranged role patterns in the family. Moreover, self-care should be encouraged to minimise the social impact of Alzheimer’s caregiving.
• **Sub-theme 4.4: Positive aspects of caregiving**

Strength-based and ecosystems practice in social work focus on the strengths and resilience of individuals to cope with life challenges. In line with these approaches, social workers should draw on the strengths and abilities of Alzheimer’s caregivers to improve their wellbeing and quality of life despite overbearing stresses and challenges. Caregivers should be supported to recognise the inherent resources they have at their disposal which they can use to counteract any difficulty. In addition, social workers should link caregivers with resources available in the community which they might find useful and support communities to develop resources required by caregivers.

4.4.1.5 **Theme 5: Support services in the community**

• **Sub-theme 5.1: Health care services**

At some stage in the Alzheimer’s disease progression, individuals suffering from the disease will become dependent on health care services. These services should therefore be accessible and responsive to the needs of persons with Alzheimer’s disease and their caregivers. Persons suffering from the disease and their caregivers should be encouraged to seek appropriate medical care, as this could alleviate the adverse symptoms of the disease and negative health outcomes associated with caregiving. It is imperative for health care professionals to be trained in the diagnosis and management of Alzheimer’s disease in order to provide effective services to these patients. The social worker, as part of the multi-disciplinary team, has an important role to play as advocate for the rights of persons with Alzheimer’s disease and those caring for them and to educate them regarding the disease.

• **Sub-theme 5.2: Home-based care services**

Home-based care services, usually provided by non-governmental organisations, are regarded as a cost effective alternative for institutional care and can complement the care provided by health care professionals. For home-based care services to be effective, home-based caregivers should be adequately trained to provide in the specific needs of persons with Alzheimer’s disease. Government should make
sufficient funding available for community home-based care services to be available to all frail older persons, as this can relieve the burden on the health care system.

- **Sub-theme 5.3: Respite care**
  Respite services can decrease the level of burden experienced by Alzheimer’s caregivers. Despite their benefits, respite care services are limited to service centres for older persons in black rural communities in Mpumalanga. These centres only provide day care to older persons. When considering the absence of residential care facilities for older persons in rural communities, alternative respite services should be developed in rural communities. Such services can include in-home respite, residential-based respite and rehabilitation programmes. It is further recommended that effective referral systems should be in place to ensure the optimal utilisation of home-based care services. Health care professionals and social workers at community level should be knowledgeable about home-based care resources available in rural communities and be able to link persons with Alzheimer’s disease and their caregivers with these resources.

- **Sub-theme 5.4: Social work services**
  People living in rural communities, especially older persons and their caregivers, experience a myriad of challenges. These challenges include poverty, limited access to resources and services, and excessive disease epidemiology. Caring for a person with Alzheimer’s disease places an additional burden on community caregivers. In view of these challenges, the need for social work services, addressing needs of caregivers, cannot be overemphasised. Community-based organisations, which provide specialised social work services to persons with Alzheimer’s disease and their caregivers, are not commonly found in rural communities. Government should revise its financing models to encourage and enable non-governmental organisations to extend service delivery to these underserviced communities. As older persons and their caregivers are often unaware of the availability of social work services, these organisations should market their services more effectively to ensure optimal utilisation.

Social workers providing services to older persons and their caregivers should be adequately trained to provide caregiver interventions and to assess the needs of
persons with Alzheimer’s disease. Social work training institutions should therefore not disregard gerontology as subject matter and should provide and promote specialised post-graduate studies in gerontology and geriatric social work. Also, social workers should be afforded the opportunity to participate in continuing education that focuses on ageing issues.

Social workers working in the field of gerontology, based on their training in community-based health care, are in a prominent position for meeting the changing social and health care needs of our ageing society. These social workers have the ability to influence government policies and advocate for improved service delivery to older persons and their caregivers, especially in rural communities where services and resources are often limited. Moreover, social workers can be instrumental in the design and implementation of community-based services and strategies which are responsive to the needs of older persons with Alzheimer’s disease and their caregivers. Such strategies can include counseling services, support groups, respite care, institutional care and home-based care services. The social worker, as part of the multi-disciplinary team in a health care setting, should advocate for the rights of persons with Alzheimer’s disease and ensure that they receive the quality of medical care they need. Community education is a core function of social workers. Therefore, social workers should mobilise communities to disseminate information about Alzheimer’s disease and the resources available in the community to provide in the needs of persons with Alzheimer’s disease and their caregivers.

- **Sub-theme 5.5: Support groups**

Support groups provide Alzheimer’s caregivers the opportunity to share personal feelings and concerns in order to overcome feelings of social isolation. As social support has the potential to lead to more favourable outcomes in both physical and mental health of caregivers and lessen the negative effects of caregiving, it is imperative to establish support groups in rural communities. For support groups to be effective, Alzheimer’s caregivers should be made aware of the availability of support groups in the community and the potential benefits of attending group sessions.
• **Sub-theme 5.6: Institutional care**

Residential care facilities are almost non-existent in rural communities. In spite of government’s policies to promote community-based and family-based care, rural persons suffering from Alzheimer’s disease often have the need for institutional care. This is especially the case where family members are unable or unavailable to provide in their care needs. It is recommended that affordable and accessible residential care facilities should be available to older persons in their own communities.

• **Sub-theme 5.7: Religious institutions**

Religious institutions are assumed to play a significant role in black rural communities and have to be utilised to the benefit of Alzheimer’s caregivers. Social workers and organisations providing support services to persons with Alzheimer’s disease and their caregivers should be encouraged to work in close collaboration with faith-based organizations. Religious institutions could assist in practical ways such as facilitating with patient referral, provide education and information for Alzheimer’s caregivers and provide respite care. Community-based organisations and government departments, providing care to older persons, could collaborate with churches to assist in disseminating information about community resources and educate the religious institution about how to offer appropriate care.

**4.4.2 Recommendations for policy**

It is imperative for policy developers in South Africa to recognise the needs of the rapidly ageing population, especially those suffering from chronic conditions such as Alzheimer’s disease. The wellbeing and protection of older persons, as a vulnerable group of our society, should be a priority on the political and service delivery agenda of national, provincial and local government. Moreover, adequate resources should be allocated to provide in the needs of these older persons, and their caregivers at community level, such as social work services, home-based care and residential care facilities.

**4.4.3 Recommendations for future research**

Future research should include a larger sample in order to test results. Using this research as a platform, future research can focus on other black rural ethnic groups.
in South Africa to determine if their needs and experiences with regards to Alzheimer’s caregiving are similar to the findings yielded by this study. Such research can focus on the factors influencing the caregiving experience and the availability and effectiveness of culturally competent caregiver interventions in black rural communities. Also, the impact of indigenous beliefs and traditional treatment practices can be researched. Barriers to accessing caregiver interventions should be determined and addressed. Research can be done with caregivers from other racial groups in rural areas nationally to compare their needs and experiences with those of this sample. Likewise, research can be done with caregivers in urban areas to determine and compare their needs and experiences with those of this sample. Most importantly, the incidence and prevalence of Alzheimer’s disease in black rural communities in South Africa should be determined conclusively to guide policy development and the provision of health and social work services.

4.5 Concluding remarks

The study aimed to explore and describe the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga. Through the study it was found that Alzheimer’s caregiving impacts significantly on the physical, psychological and social wellbeing of caregivers in a number of ways.

The research emphasised the need to intervene with persons suffering from Alzheimer’s disease, and their caregivers, to improve their overall psychosocial functioning and wellbeing. Further research should be done with a more diverse target group to determine if the needs and experiences of Alzheimer’s caregivers correlate or differ across cultures.

The goal and objectives of this research study were accomplished. This was done by means of a thorough literature study which generated information that would broaden the researchers’ knowledge on the subject of caregiving in the context of Alzheimer’s disease. Data were collected from eleven participants. The research data formed the basis for the empirical chapter of this study. This allowed the researcher to make key findings after the data were analysed. The researcher was also able to come to specific conclusions and recommendations based on the study.
The researcher is of the opinion that the research question was adequately answered by this study and that it provided insight into the needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga.
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APPENDIX 1

ETHICAL APPROVAL LETTER
2012-02-29

Dear Prof Lombard

Project: The needs and experiences of caregivers of persons with Alzheimer’s Disease living in black rural communities in Mpumalanga

Researcher: Bosch JN
Supervisor: Dr CL Carbonatto
Department: Social Work and Criminology
Reference number: 10469924

I am pleased to be able to tell you that the above application was approved by the Postgraduate Committee on 14 February 2012 and by the Research Ethics Committee (with comment) on 23 February 2012. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof John Sharp
Chair: Postgraduate Committee & Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za
APPENDIX 2

LETTER OF PERMISSION FROM AGE-IN-ACTION
(MPUMALANGA)
23 January 2012

The Researcher
Mr. Johan Bosch
Per e-mail

Dear Mr Bosch

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH INTERVIEWS WITH CLIENTS OF AGE-IN-ACTION (MPUMALAGA)

In reference to your letter dated 20/01/2012 received with thanks.

The necessity of research in the field as stipulated in your proposal is of cardinal importance to our sector of service delivery.

We would therefore support your research by providing permission to conduct interviews with our clients/beneficiaries in the manner prescribed in your letter.

We thank you for the proposed research and look forward to assist you in this regard.

Yours sincerely

Ms. S.C. van Niekerk
Provincial Director
APPENDIX 3

LETTER OF PERMISSION FROM ALZHEIMER’S SOUTH AFRICA (MPUMALANGA)
23 January 2012

Dear Mr Johan Bosch

Thank you so much for your letter dated 20th January 2012.

It is a privilege to assist you with your research. Alzheimer’s South Africa will find this information of great value. The caregivers work with the persons with Alzheimer’s and their needs impact the on families and communities if not met. We are constantly expanding the areas we serve and such research will be invaluable for the implementing of caring programs.

Permission is granted to deal with the caregivers looking after person with Alzheimer’s and we would like to accompany you to the interviews. This is the area we work in mostly and has the greatest need for this information.

Please contact me so we can set up the necessary appointments.

Yours sincerely

Maureen Rochat
Chairperson: Mpumalanga Region
APPENDIX 4
INTERVIEW SCHEDULE
Interview schedule

Research for MSW (Health Care)

Principal investigator: Johan Bosch (10469924)

The needs and experiences of caregivers of persons with Alzheimer's disease living in black rural communities in Mpumalanga

General

- Age of participant
- Gender of participant
- Marital status of participant
- Relationship of participant with person suffering from Alzheimer’s disease
- Diagnosis of person with Alzheimer’s disease
- Level of educational attainment of participant
- Household composition of participant

Caregiving

- Caregiver remuneration and income
- Hours per day and week providing care to person with Alzheimer’s disease
- Caregiving tasks provided
- Caregiver training received

Indigenous issues about Alzheimer’s disease

- Knowledge of community about Alzheimer’s disease
- Attitudes of community towards person with Alzheimer’s disease and participant
- Indigenous beliefs about Alzheimer’s disease
- Traditional treatment practices
  - Traditional healers’ diagnosis of Alzheimer’s disease
  - Traditional healers’ treatment of Alzheimer’s disease

Caregivers’ understanding of Alzheimer’s disease

- Alzheimer’s disease as medical condition
- Causes of Alzheimer’s disease
- Symptoms of Alzheimer’s disease
- Treatment of Alzheimer’s disease
- Prognosis of Alzheimer’s disease

Impact of caregiving

- Impact of caregiving on participants’ physical wellbeing
  - Physical symptoms experienced
  - Medical treatment received
- Impact of caregiving on participants’ psychological wellbeing
  - Depression
  - Stress
  - Loneliness
  - Caregiver burden
- Impact of caregiving on participants’ social functioning
  - Role conflict
  - Social activities
  - Social isolation and social support
  - Financial implications of caregiving
- Positive aspects of caregiving

Support services in the community

- Health care services
  - Accessibility of health care services
  - Type of health care services
  - Attitude of health care professionals
  - Diagnosis and treatment received from health care services
- Home-based care services
  - Accessibility of home-based care services
  - Utilisation of home-based care services
- Respite care
  - Accessibility of respite care services
- Utilisation of respite care services
- Service centres for older persons

❖ Social work services
  - Accessibility of social work services
  - Utilisation of services
  - Awareness of Alzheimer’s South Africa and Age-in-Action

❖ Support groups
  - Accessibility of support groups
  - Utilisation of support groups

❖ Residential care facilities (institutional care)
  - Availability
  - Attitude of participant towards admission of person with Alzheimer’s disease to a residential care facility
  - Outcome of previous applications for admission to a residential care facility

❖ Religious institutions
  - Church attendance
  - Religious views of caregiving
APPENDIX 5

LETTER OF INFORMED CONSENT
LETTER OF INFORMED CONSENT

SECTION A: RESEARCH INFORMATION

Principal Investigator: Mr JN Bosch – MSW (Health Care)
Student Nr: 10469924

Dear participant

Research Project: The needs and experiences of caregivers of persons with Alzheimer’s disease living in black rural communities in Mpumalanga.

1. Purpose of the study
The researcher is a qualified social worker by profession and a MSW (Health Care) student at the Department of Social Work and Criminology, University of Pretoria. In his professional capacity, he has been involved with persons suffering from Alzheimer’s disease and their caregivers and is interested in further exploring the needs and experiences of such caregivers in black rural communities in Mpumalanga. It is well recognised that Alzheimer’s disease does not only affect the person with the condition but also impacts on the caregiver. Research indicates that caregiving is generally provided by informal carers in the community. There is however very little research or literature indicating the burden of Alzheimer’s disease on the caregiver in rural areas of South Africa, where access to health and social services and residential care facilities is often limited.

Your participation in the search to understand the essence of this caregiving experience would be helpful to many other people in similar situations.

2. Procedures
An interview of approximately 90 minutes will be arranged and conducted with you at a time and place that will be convenient for you and the researcher. This interview will be audio-taped with your permission and thereafter it will be transcribed in writing by the researcher. Personal data which can enrich the data for this study will be used with you permission. The information you share will be utilized in the research report.

A letter of the alphabet will be assigned to you at the interview by the researcher, which will be used in referring to any information in the research report, without ever being able to be linked in any way to you identity. Articles in scientific journals will also be published on the results of the study. This study protocol has been submitted to the Postgraduate and Ethics Committees of the Faculty of Humanities, University of Pretoria, for required approval.

The research data collected will be kept in a safe place for 15 years in the Department of Social Work and Criminology at the University of Pretoria as prescribed, should this data be used for a follow-up study and thereafter it will be destroyed. All signed letters of informed consent will be
kept in a confidential file and you will receive a copy of the letter of informed consent. Only the researcher will have access to this information and the recorded interviews.

3. Risks and Discomfort
It is possible that the sharing of certain experiences may be emotionally painful for you. Possible risks or harm that could emanate from participation in the research will be dealt with great sensitivity. Debriefing will be done by the researcher at the end of the interview. Should it be necessary, counselling will be arranged by the researcher with a social worker from Age-in-Action or Alzheimer’s South Africa.

4. Benefits of research
You may not benefit directly from this research, (no material gain) but may benefit indirectly, because the information obtained by means of this research, will help to explain and give a better understanding of the needs and experiences of caregivers of persons with Alzheimer’s disease in black rural communities.

5. Confidentiality and anonymity
The data collected will remain anonymous and confidential, as your name will not be used in the report, but a letter of the alphabet will be assigned to you as participant at the interview, which only the researcher will know is linked to you. All data collected will remain confidential and will never be linked to you.

6. Financial compensation
No form of remuneration or compensation will be provided to you for you participation in the research.

If you have any questions during this study, you can contact the researcher.

Yours sincerely,

Johan Bosch

Researcher
Date:

Contact details of the researcher:
Mr Johan Bosch can be contacted at (013) 750 1001 (office hours) or at 082 433 8719 (all hours) if there are any questions or concerns.
SECTION B: RESEARCH CONSENT

I, ___________________________ (Full name and surname of participant) hereby acknowledge that I have been informed about the research study. I am aware of what is required of me as a participant. I have read and understand how the research procedure will be followed. I have asked the relevant questions I may have had and I am aware of the confidential nature of the study. As a participant, I also understand that my identity will be kept anonymous. Finally, if at any point I choose to withdraw from the study, I understand I will not suffer any negative consequences.

I will receive a signed copy of this informed consent form.

Please complete the form below:

Participant:

Signature: _____________________________

Date: _____________________________

Researcher

I have explained the study to the participant, and provided him/her with a copy of the letter of informed consent.

Name: Johan Bosch

Signature: _____________________________

Date: _____________________________
APPENDIX 6
DECLARATION OF LANGUAGE EDITING
RE: DECLARATION OF LANGUAGE EDITING

I, Marita Oosthuizen (ID Number 740126 0159 085), hereby declare that I edited the dissertation of Mr Johan Nico Bosch entitled:

*The Needs and Experiences of Caregivers of Persons with Alzheimer’s Disease Living in Black Rural Communities in Mpumalanga*

Without viewing the final product.

Yours sincerely,

Marita Oosthuizen

Managing Member: Chatworth Consulting

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