

**LIVING WITH ALZHEIMER'S DISEASE IN NAMIBIA:
THE ADULT CHILD, THE OLDER PARENT AND THE
DECISION TO INSTITUTIONALISE**

By

ELMI PRETORIUS

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ABSTRACT

LIVING WITH ALZHEIMER'S DISEASE IN NAMIBIA: THE ADULT CHILD, THE OLDER PARENT AND THE DECISION TO INSTITUTIONALISE

Researcher: Elmi Pretorius
Department: Social Work and Criminology, University of Pretoria
Supervisor: Prof. C.E. Prinsloo
Degree: MSW

Population ageing is a global phenomenon, and although a victory in development, it brings about several social, economic and cultural challenges. One of these challenges is the deteriorating health of older persons, which inevitably increases the demand for health care and long-term care services. Older persons become more disposed to ill health, and although mental health problems are not an inevitable part of ageing, the number of older persons affected by mental health problems continue to surge. As the number of older persons with dementia continue to rise, public health systems will be regularly weighed down by the need to deal with the care and treatment of those living with dementia. Alzheimer's disease (AD), which is the most common type of dementia, is one of the most consuming mental health disorders that are diagnosed in older persons. AD is a family disease, and the impact of this neurological disorder is felt throughout the family system and all its subsystems.

The purpose of this research study was to explore and discuss the experiences of adult children, who made the decision to place their parents diagnosed with AD in the specialised care facility, established by Alzheimer's Dementia Namibia (ADN), in Swakopmund. Receiving a dementia diagnosis is not something one looks forward to, and when an older parent is diagnosed with AD the adult children experience numerous emotions. Persons with dementia (PWD) and their family members often find themselves alone in the dementia journey, and they receive little or no support when confronted with the many losses that occur as a result of the disease. Ideally, older persons want to live in their own homes with their families, but the harsh reality

is that as the disease progresses PWD will need to be institutionalised to ensure that their specific care needs are met. One of the most difficult decisions that the adult child will eventually have to make is to place their older parent with dementia in a care facility.

An in-depth literature study was done on AD as the most common form of dementia, the impact AD has on the parent-child relationship throughout the life cycle was explored, the need for specialised care facilities was discussed, and the effect that the rising number of PWD will have on the health care system of Namibia was reported. The researcher approached this study from the qualitative research approach, which allowed her to immerse herself in the experiential world of each participant. The empirical findings showed that AD is a family disease which negatively effects relationships throughout the family system, changes the dynamics of the family, results in great losses within relationships, and leaves the adult child with only a memory of who their parent once was. Participants affirmed that a huge gap exists in Namibia regarding knowledge and understanding of dementia, awareness raising, and quality dementia care. Although the study population was small, the data collected was rich and enabled the researcher to make recommendations for future research, practice and the Namibian government

The research question was answered in that the experiences of adult children, who made the decision to place their parents diagnosed with Alzheimer's disease in the ADN Care Farm Namibia were explored; more research will need to be conducted to conclude these findings. Conclusions were deduced and recommendations made based on the results of this study.

KEYWORDS

- Living
- Alzheimer's disease
- Adult child
- Older parent
- Institution
- Institutionalisation

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Table 1: ABBREVIATIONS

UN	United Nations
WHO	World Health Organization
AD	Alzheimer's disease
ADLs	Activities of daily living
ADN	Alzheimer's Dementia Namibia
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DALYs	Disability Adjusted Life Years
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
LAC	Legal Assistance Centre
LTCFs	Long-term Care Facilities
NCDs	Neurocognitive disorders
PWD	Persons with dementia
MOHSS	Ministry of Health and Social Services
N\$	Namibian dollar
QoL	Quality of life
NMBF	National Medical Benefit Fund
PSEMAS	Public Service Employment Medical Scheme
SCC	Social Security Commission
SDG's	Sustainable Development Goals
UHC	Universal Health Coverage
UNDP	United Nations Development Programme

CHAPTER 1

INTRODUCTION TO THE RESEARCH STUDY

1.1 INTRODUCTION

In the world of today, change is erratic and abrupt, and it is essential to note that included in this ever-changing world is the anticipation that global ageing is a highly foreseeable and long-term trend (Schwab, 2012:2; United Nations (UN), 2017a:2). Therefore, population ageing and the impact thereof on all sectors of society cannot and should not be ignored. Population ageing, which refers to “the increasing share of older persons in the population”, can be observed in practically every country in the world with the number and percentage of older persons rising daily and growing faster than the numbers of people in any other age group (Chan, 2012:3, UN, 2015:1; UN, 2017a:3). Statistics released by the UN (2017a:2) indicate:

The global population aged 60 years or over numbered 962 million in 2017, more than twice as large as in 1980 when there were 382 million older persons worldwide. The number of older persons is expected to double again by 2050, when it is projected to reach nearly 2.1 billion. Globally, the number of people aged 80 years or over is growing even faster than the number of older persons overall. Projections indicate that the number of people aged 80 or over worldwide will increase more than threefold between 2017 and 2050, rising from 137 million to 425 million.

People are living longer than before, and these additional years of life and the restructuring of society have profound implications for each individual and the communities in which they live (Chan, 2012:3; Osotimehin, 2012:11; World Health Organization (WHO), 2016:1). Although a victory of development, population ageing also brings about social, economic and cultural challenges to individuals, families, societies and the global community (Chan, 2012:3; United Nations Population Fund & HelpAge International, 2012:12). One of these challenges is the failing health of older persons, which increases the demand for health care and long-term care services (United Nations Population Fund & HelpAge International, 2012:29). As people age, they become more disposed to disease or illness, and many adults who are still alive at 80 years of age or older are likely to have some type of impairment (Santrock, 2015:527; Sigelman & Rider, 2015:157). Mental health problems are not an inevitable

part of ageing, however, due to population ageing the number of older persons affected by mental health problems have increased (United Nations Population Fund & HelpAge International, 2012:29). One of the most consuming mental health disorders diagnosed in older persons is dementia, and nothing seems to scare older adults more about ageing than the thought that they might become 'senile' (Sigelman & Rider, 2015:531). Worldwide over 50 million people are living with dementia (WHO, 2017c). The number of people living with dementia is projected to reach 82 million in 2030 and rise to between 131 and 150 million by 2050 as populations continue to age (Rees, 2015; WHO, 2017c). Alzheimer's disease (AD) is the most common type of dementia, and accounts for an estimated 60 to 80 percent of all diagnosed cases (Alzheimer's Association, 2018a:5; WHO, 2017c). The researcher will focus primarily on AD, as it is most commonly diagnosed in the elderly.

Considering the above, the purpose of this research study is to explore and discuss the experiences of adult children, who made the decision to place their parents diagnosed with AD in the specialised care facility, established by Alzheimer's Dementia Namibia (ADN), in Swakopmund. In January 2009, Mr. Berry Holtzhausen founded the Michelle Group Trust, in honour of a young girl named Michelle who passed away in a tragic car accident (ADN, [sa]). Mr Holtzhausen became aware that Namibia lacked a facility which catered for the specific needs of people with AD, and it is against that backdrop that the Michelle Group Trust established Dementia Namibia in January 2012 with the opening of the Dementia clinic at Yakandonga, a farm between Otjiwarongo and Kalkveld (ADN, [sa]). In 2015 the care facility, renamed to ADN Care farm, and all its residents were relocated to Swakopmund.

The following key concepts apply to the research study:

- **Living:** Living is defined as "... a way or style of life, a particular manner, state, or status of life" (Dictionary.com, 2018a). The *Merriam-Webster Online Dictionary* (2018) states the following as synonyms for 'living': "functional, functioning, and operating". Therefore, for this research study, 'living with' will be used to refer to the life of adult children whose parents were diagnosed with AD in Namibia; how a diagnosis of AD effected the adult child's functioning and operation in their day to

day lives; and the way of life for the adult child and their older parent diagnosed with AD, specifically in the Namibian context.

- **Alzheimer's disease:** The most common form of dementia is AD (Bright Focus Foundation, 2018; Sarafino & Smith, 2012:315; WHO, 2017c), a “progressive neurodegenerative brain disease characterised by a steady decline in memory, ability to learn, reasoning, judgment, communication, activities of daily living (ADLs), and behaviour” (Grossberg, 2010:196).
- **Adult child:** Santrock (2015:14) differentiates between early and middle adulthood. Early adulthood is the term used to refer to the developmental period that stretches from the early twenties throughout the thirties. During this life phase young adults establish personal and economic independence, they grow in their careers, and for many it is a time of choosing a spouse and starting a family (Santrock, 2015:14). Furthermore, this development phase is significant for the establishment of adult roles and responsibilities (Sigelman & Rider, 2015:5). Santrock (2015:14) further states that middle adulthood is “the development period from approximately 40 to about 60 years of age. It is a time of expanding personal and social involvement and responsibility; of assisting the next generation in becoming competent, mature individuals”. Considering the above, in this research study, the term ‘adult child’ will thus refer to any person between the age of 20 and 59 years who is the biological child of a parent with AD.
- **Older parent:** Late adulthood refers to the “development period that begins during the sixties or seventies and lasts until death” (Santrock, 2015:14). Parent is the term used to refer to “a person’s father or a mother” (*English Oxford Living Dictionaries*, 2018; *Dictionary.com*, 2018b). Thus, in this research study the term ‘older parent’ will refer to the father and/or mother 60 years and older, of an adult child, living in the ADN Care Farm.
- **Institution:** An institution is defined as “an organisation providing residential care for people with special needs” (*Oxford Dictionaries*, 2018). In this study, the term institution will therefore refer to the ADN Care Farm in Swakopmund, which provides specific and specialised treatment for individuals diagnosed with dementia, a private organisation established in 2012.
- **Institutionalisation:** Institutionalise is defined as “to place or confine in an institution, especially one for the care of mental illness, alcoholism, etc.” (*Dictionary.com*, 2018c). Thus, in this study, the term institutionalisation will be used

to refer to the placement of a parent who, due to a diagnosis of dementia and AD, in the private ADN Care Farm in Swakopmund.

1.2 LITERATURE REVIEW

The researcher will focus primarily on AD; however, to contextualise AD within this study, the researcher will briefly discuss dementia, and elaborate on the two most common types of dementia diagnosed in the elderly, namely: AD and Vascular dementia.

1.2.1 DEFINING DEMENTIA

In 1684, Thomas Willis used the word 'dementia' to refer to people believed to be out of their minds; followed by a definition noted in the 1762 edition of the Blanchard's Popular Physical Dictionary stating that dementia is an "extinction of the imagination and judgment" (Keady, Clarke & Adams, 2003:6). The above suggests that dementia destroys the essential aspects that make the person human. The Alzheimer's Association (2018b) notes that dementia is often wrongly labelled as "senility" or "senile dementia," which speaks to the previously widespread but incorrect belief that serious mental decline is a typical part of aging and that older people are completely dependent on others. Luckily, research has come a long way since the 1600's, helping to transform the misguided definitions and ideas about dementia.

Dementia is not a condition in itself; it is an umbrella label to refer to a group of conditions and diseases that develop when nerve cells in the brain die or no longer function causing irreversible damage to the brain (Aigbogun, Stellhorn, Krasa & Kostic, 2017:51; Alzheimer's Association, 2018b; Souter, 2015:47; Thies & Bleiler, 2012:132). The death or malfunction of these nerve cells, called neurons, ultimately results in changes in one's memory, behavior, and ability to think clearly (Thies & Bleiler, 2012:132). The Alzheimer's Society (2014a:2) asserts that although these changes are often small to start with, dementia is a progressive disease, and thus the symptoms gradually worsen over time. As dementia progresses, the individual's behavior often seems unusual or out of character, and these changes are challenging not only for the patient, but also for the family members (Alzheimer's Society, 2014a:2). Eliopoulos

(2014:442, 443) supports the above by stating that dementia is the “irreversible impairment in cognition caused by disease or injury to the brain”; and that impairs cognition, and threatens the ability to communicate, function independently, make decisions and understand events. It is important to note that, although dementia is more common with increasing ageing, it is not a normal part of ageing and it is not the result of increasing age (Sigelman & Rider, 2015:531). Dementia is a term that “refers to a progressive loss of cognitive functions that often occurs at old age” (Sarafino & Smith, 2012:315). Eliopoulos (2014:442) continues to state that older adults do not welcome arthritis, heart disease, and other physical ailments. However, these conditions tend to be feared less than the loss of normal cognition. Dementia is a crippling and merciless disease that consumes and eventually destroys the very being of the diagnosed individual.

In 2013, the American Psychiatric Association released the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), in which dementia is incorporated into the diagnostic categories of major and mild neurocognitive disorders (Dementia Australia, 2018:1). The American Psychiatric Association (2013:591) states the following:

The neurocognitive disorders (NCDs) (referred to in DSM-IV as “Dementia, Delirium, Amnesic, and Other Cognitive Disorders”) begin with delirium, followed by the syndromes of major NCD, mild NCD, and their etiological subtypes. The major or mild NCD subtypes are NCD due to Alzheimer’s disease; vascular NCD; NCD with Lewy bodies; NCD due to Parkinson’s disease; frontotemporal NCD; NCD due to traumatic brain injury; NCD due to HIV infection; substance/medication-induced NCD; NCD due to Huntington’s disease; NCD due to prion disease; NCD due to another medical condition; NCD due to multiple etiologies; and unspecified NCD. The NCD category encompasses the group of disorders in which the primary clinical deficit is in cognitive function, and that are required rather than developed. Although cognitive deficits are present in many if not all mental disorders (e.g., schizophrenia, bipolar disorders), only disorders in which impaired cognition has not been present since birth or very early life, and thus represents a decline from previously attained level of functioning.

Furthermore, the American Psychiatric Association (2013:591) states that the term “dementia” is maintained in the DSM-5 for continuity and may be used in settings where physicians and patients are familiar with this term. Neurocognitive disorder is a term widely used and often preferred for conditions affecting younger persons, such as

impairment due to traumatic brain injury; on the contrary, dementia is the customary term for disorders like the degenerative dementias that are normally diagnosed in older adults (American Psychiatric Association, 2013:591). It is against this backdrop that the researcher will refer to the term “dementia”, instead of “neurocognitive disorder”, in this study as it is the term the research participants and the public are more familiar with.

1.2.2 TYPES OF DEMENTIA

Dementia is a term used to portray several conditions or illnesses that affect a person’s brain functioning, such as AD, which results in them experiencing a decline in their cognitive skills (Alzheimer’s Association, 2018b; Moore & Jones, 2012:21). Major and mild NCDs exist on a range of cognitive and functional impairments (American Psychiatric Association, 2013:607):

Major NCD corresponds to the condition referred to in the DSM-IV as dementia, retained as an alternative in the DSM-V. The core feature of NCDs is acquired cognitive decline in one or more cognitive domains based on both 1) a concern about cognition on the part of the individual, a knowledgeable informant, or the clinician, and 2) performance on an objective assessment that falls below the expected level or that has been observed to decline over time.

The overall frequency estimates for dementia, largely congruent with major NCD, are approximately 1% - 2% at age 65 years, and as high as 30% by the age of 85 (American Psychiatric Association, 2013:608). For this study, dementia will refer to disorders such as degenerative dementias normally diagnosed in older adults (American Psychiatric Association, 2013:591), with specific reference made and focus placed on AD.

- **Alzheimer’s disease (AD)**

By the end of his life, Dr. Alois Alzheimer (1864–1915) had proven himself to be a versatile clinical psychiatrist and prominent expert on the “histopathology of the cerebral cortex” (Toodayan, 2016:47). In 1906, he performed an autopsy on the brain of his patient and ‘test subject’, Frau Auguste Deter, and he discovered that her death was due to a “peculiar and unusual disease of the cerebral cortex” (Alzheimer’s disease International, [sa]; Toodayan, 2016:54). The “disease of forgetfulness”, which

we now know as AD was named after Dr. Alzheimer (Mental Health Gateway, 2016; Souter, 2015:67) who, despite the lack of interest from his peers and those in the scientific community (Toodayan, 2016:54), was determined to find comparable cases and prove that AD was real and worth medical attention.

AD is the most common type of dementia (Alzheimer's Society, 2014a:1; Sarafino & Smith, 2012:315; Eliopoulos, 2014:444). It is a progressive, consuming brain disorder, characterised by a deterioration of attention, memory and personality; as the disease continues to progress more parts of the brain are damaged and more symptoms develop (Alzheimer's Society, 2017:3; Sarafino & Smith, 2012:315). Due to the progressive nature of the disease, the cognitive functions of people with AD do not disappear all at once, but unfortunately, the first cognitive functions to go are attention and memory (Alzheimer's Society, 2014a:2; Sarafino & Smith, 2012:315). The symptoms of this progressive, degenerative disease usually develop gradually with the progression of the disease varying from person to person (Alzheimer's Association, 2018a:368; Eliopoulos, 2014:445). Although AD is said to have a slow onset often accompanied by mild symptoms (Souter, 2015:75), the grim reality remains that as the disease progresses and intensifies, so does the patient's memory loss. The Alzheimer's Society of Canada (2018a) asserts that although each person living with AD is affected in diverse ways, the reality is that AD is a fatal disease (Alzheimer's Association, 2018a:368) that ultimately affects all facets of a person's life, including "how they think, feel, and act".

- **Vascular dementia**

Vascular dementia is the second most common type of dementia. It is caused by damaged, narrow or clogged up blood vessels that supply brain cells with oxygen, which leads to loss of blood flow to the brain and ultimately results in irreversible brain damage (Alzheimer's Society, 2017:3; Dementia Services Information and Development Centre, 2014; Souter, 2015:80). The symptoms can occur suddenly following one large stroke, or over time through a series of small strokes, or because of damage to or disease of small blood vessels deep in the brain (Alzheimer's Society, 2017:3). The effect of vascular conditions on cognitive skills varies extensively, "depending on the severity of the blood vessel damage and the part of the brain it

affects” (Alzheimer’s Association, 2016:2). Many diagnosed with vascular dementia have difficulties with problem-solving or planning, thinking quickly and concentrating, and the symptoms of vascular dementia vary and may overlap with those of AD (Alzheimer’s Society, 2017:3, 4). Whereas AD is characterised by memory problems, depending on which parts of the brain were affected by the stroke, patients with vascular dementia may or may not have memory disturbances (Alzheimer’s Association, 2016:2; Souter, 2015:89). Physical symptoms of vascular dementia may be most evident when they occur soon after a major stroke (Souter, 2015:89). Like other types of dementia, vascular dementia shortens the lifespan of an individual diagnosed with the disease, and data collected in previous studies have suggested that persons who develop dementia after a stroke are immediately inclined to a shorter lifespan (Alzheimer’s Association, 2016:3).

Although AD and Vascular dementia are the two most common types of dementia, there are many other types of dementia that are just as difficult to live with. The third most common type of dementia is dementia with lewy bodies (DLB), which is caused by small round clusters of protein that build up inside nerve cells in the brain (Alzheimer’s Research UK, 2018). Lewy Bodies affect the nerve cells that are in the parts of the brain that control thinking, memory and movement, and lewy bodies are also further blameable for the damage that causes movement difficulties in Parkinson’s disease (Alzheimer’s Research UK, 2018). DLB causes changes in the brain that are typical of AD, and as such it is sometimes difficult to tell the difference between DLB and AD (Alzheimer’s Research UK, 2018). Other types of dementia include Frontotemporal dementia (FTD), mixed dementia, young-onset dementia, Creutzfeld-Jakob disease (CJD), Alcohol related brain damage, and HIV-related cognitive impairment (Alzheimer’s Society, 2019).

Although all the different types of dementia mentioned above are sure to have an impact on the parent child relationship and the family system, AD is the most common form of dementia and the researcher will focus primarily on AD in this research study. With an increase in the number of older people and diagnoses of AD, the care of such a person needs attention.

1.2.3 CARE MANAGEMENT

Due to the complex nature of dementia, the diverse nature of the family, and the differing healthcare, social and welfare services across the country it is quite problematic to establish best practices to improve the quality care for those living with dementia (Zabalegui, Hamers, Karlsson, Leino-Kilpi, Renom-Guiteras, Saks, Soto, Sutcliffe & Cabrera, 2014:176). Globally dementia presents many challenges for primary care, and while early or timely diagnosis has received much attention, the long-term management of the patient with dementia in primary care has been neglected (Wilcock, Jain, Griffin, Thuné-Boyle, Lefford, Rapp & Iliffe, 2016:362). Wilcock et al. (2016:362) further assert that management of the primary care of people living with dementia is poorly understood, and medical practitioners have reported limitations in several aspects of dementia management. On a global scale there is a greater awareness that as the population continues to age and the number of people living with dementia continues to rise, it is essential that new approaches be developed to enable Persons with Dementia (PWD) to live well in their communities and families for as long as possible (Henwood & Downs, 2014:29).

1.2.3.1 Population ageing, dementia and a public health approach

Populations around the globe are ageing at a rapid rate, presenting both opportunities and challenges globally (Beard & Bloom, 2015:658; Chan, 2012:3). Population ageing has been attracting the attention of people in policy, political and even media circles, with one of the primary reasons for this attraction being that the quick ageing of humankind is possibly the most striking and dynamic feature of contemporary demography (Beard, Biggs, Bloom, Fried, Hogan, Kalache & Olshansky, 2012:4). Population ageing is to become one of the most significant social transformations of the twenty-first century, with implications for nearly all sectors of society, including labour and financial markets, the demand for goods and services, such as housing, transportation and social protection, as well as family structures and intergenerational ties (American Federation for Aging Research, 2014; Chan, 2012:3; Osotimehin, 2012:11). As such, the influence of population ageing on public health and national economies is inevitable and dramatic (Beard et al., 2011:4) and ultimately, unavoidable.

1.2.3.2 Public health care

There is a greater realisation that public health measures will play an imperative role in the effort to guard world populations from cognitive impairment and dementia (Beard & Bloom, 2015:658), with recent data showing a considerable rise in the number of people living with dementia globally (Beard & Bloom, 2015:658; WHO, 2017), this being fundamentally driven by population ageing (Frankish & Horton, 2017:2614). For as long as no cure is found, the enormous cost of the disease will challenge health systems to confront the expected increase in numbers of PWD (Frankish & Horton, 2017:2614; Olanrewaju, Clare, Barnes, Brayne & CFAS, 2015:151; WHO & Alzheimer's Disease International, 2015:2). As the population continues to age, the numbers of older adults diagnosed with AD rapidly increase (Naqvi, 2017), directly raising various social and economic concerns for both the family and the government, particularly regarding care management (Nikmat, Hawthorne & Al-Mashoor, 2015:115; Naqvi, 2017). Public health systems will be gradually weighed down by the need to deal with the care and treatment of those living with dementia (Bialystok, Abutalebi, Bak, Burke & Kroll, 2016:56).

In an article published in one of Namibia's most read newspapers, the Namibian, with the headline reading "*Lack of frail care policy strands the elderly*", Hartman (2015:4) attempts to reveal what the elderly in this society need to deal with. Hartman (2015:4) asserts that a record number of Namibia's frail elderly are struggling in the absence of a State frail care policy and that those with the means at their disposal can afford to spend their last days in a private facility or acquire a nurse to manage their lives in the comfort of their homes. However, this is not the case for most of Namibia's older persons. The WHO and Alzheimer's Disease International (2015:2) state:

The challenges to governments to respond to the growing numbers of people living with dementia are substantial. A broad public health approach is needed to improve the care and quality of life of people living with dementia and family caregivers. The aims and objectives of the approach should either be articulated in a stand-alone dementia policy or plan or be integrated into existing health, mental health or old-age policies and plans.

Currently, Namibia has no frail care policy (Hartman, 2015:4; New Era, 2016). In an article published in the New Era (2016) newspaper, a government owned newspaper

in Namibia, it was reported that the Ministry of Health and Social Services (MOHSS) has recognised the need for the development of a comprehensive national policy on older persons, which would guarantee their improved protection and care. This policy will further aim to ensure the rights, protection and care of senior citizens, and focus on “mainstreaming ageing in all national issues, policies and legislation” (New Era, 2016). Unfortunately, this national policy has yet to be tabled or released. Beard and Bloom (2015:658) assert that it is of utmost importance that a broad public health approach to population ageing be adopted, not just locally but globally, that “responds to the needs, capacities, and aspirations of older people and the changing contexts in which they function”.

On the 11th of April 2018, the President of the Republic of Namibia, His Excellency Dr. Hage G. Geingob (Republic of Namibia, 2018:41) delivered the annual State of the Nation Address. He stated the following:

The administration of targeted social grants continues to uplift livelihoods. During the period under review one-hundred-and-sixty-five-thousand-three-hundred-and-seventy-six (165,376) elderly citizens were registered recipients of the monthly grant, compared to one hundred-and-fifty-nine-thousand-three-hundred-and-fifteen (159,315) the preceding year. An increase of six-thousand-and-sixty-one (6,061) beneficiaries from the previous year. It also represents a coverage rate of 99 percent. The monthly allowance was also increased to 1,200 Namibian Dollars per month, in line with Government’s promise. This monthly grant towards our senior citizens is transformational because it raises household income and benefits more people beyond the direct beneficiary.

In 2015, the old age pension grant in Namibia increased from a mere N\$600.00 (Six Hundred Namibian Dollars) to N\$1000.00 (One Thousand Namibian Dollars) as approved in the budget for the 2015 fiscal year (Geingob, 2015:5). The president held true to his promise, and the Namibian elderly now receive double the amount they did in 2015. Although this is an achievement for the nation, with a basic income of N\$1200.00 the majority of Namibia’s frail elderly cannot afford to live in a care facility specifically designed to meet their needs, and they are thus forced to stay alone or with family members. Numerous cases of family members misusing the old age pension of their elderly parents or grandparents have surfaced in local news and have been reported to the Namibian Police Force. During the 2015 ‘World Elder Abuse Awareness Day’, the then Mayor of Windhoek, Honourable Muesee Kazapua, asserted

that the elderly suffer “emotional, physical and financial abuse at the hands of their relatives who are supposed to be taking care of them” (Kahiurika, 2015:3), and that much of the abuse is not discussed in public and therefore goes unnoticed.

1.2.4 ALZHEIMER’S DISEASE

Most sufferers of AD live at home and receive care from their spouses or adult children (Hazzan, Shannon, Ploeg, Raina, Gitlin & Oremus, 2016:2; Palmer, 2013:224; Sarafino & Smith, 2012:316). Spouses are the first line of defence when sickness strikes, followed by adult children. However, compared with spouses, adult children provide care over a longer period (Schwartz & Scott, 2010:418). Caring for someone with degenerative dementias, such as AD, can be a frustrating, traumatic and stressful process; and the sombre reality is that the process of caring for someone with dementia becomes more difficult as the disease progresses (Schoenmakers, Buntinx & Delepeleire, 2010:191; Souter, 2015:172). The tremendous burden of caring for someone with AD at home becomes physically and emotionally overwhelming (Fulmer & Li, 2017:16; Sarafino & Smith, 2012:316). Caring for a family member with AD is linked to greater physical, emotional, and economic stress, and can have a momentous impact on those family caregivers’ health-related quality of life (Alzheimer’s Association, 2018a:388; Fulmer & Li, 2017:161; Hazzan et al., 2016:2; Sinha, Desai, Prakash, Kushwaha & Tripath, 2016:86).

The emergence of nuclear family units has changed the roles and functions of the individuals in a family (Eliopoulos, 2014:36), and with adult children starting their own families and careers they are often unable to provide their frail parents with the safe and structured environment they require, forcing them to place their parents in an institution. Eliopoulos (2014:448) continues that as patients regress, their self-respect, individual worth, autonomy, and individuality may be jeopardized, which may in return result in loved ones viewing their demented family member as a stranger living in the body that once housed the person they knew. Caregivers may become so focused on meeting their loved one’s needs that they neglect their own (Schwartz & Scott, 2010:420). These caregivers often face tremendous burnout as they are unaware of the resources available to them.

1.2.4.1 Alzheimer's disease and institutionalisation

AD is a fast-developing global epidemic (Hampel, Prvulovic, Teipel, Jessen, Luckhaus, Frölich, Riepe, Dodel, Leyhe, Bertram, Hoffmann & Faltraco, 2011:718), and accounts for an estimated 60 – 80% of all dementia cases among the elderly (Alzheimer's Association, 2017:327). One of the obstacles that will need to be addressed as the global population continues to age and the number of older persons living with AD continues to rise, is the increasing need and demand for both community and residential aged care facilities worldwide (BDO, 2014:3; Mitchell, Harvey, Draper, Brodaty & Close, 2017:58). Many older persons, including those with dementia, prefer to live at home in their communities, but as the illness continues to progress and the cognitive and physical impacts become greater, they need more and more support from family members and paid caregivers if they are to remain living at home (Hazzan et al., 2016:2; Miltea, Shulver, Killington, Bradley, Ratcliffe & Crotty, 2015:9; Nikmat et al., 2015:115; Sparks, 2008:65). Eventually most people living with dementia will need additional support that cannot be provided at home, and although home based care is often preferred by both the family and the patient, transfer to a nursing home or residential care facility becomes unavoidable, especially during the later stages of a degenerative dementia diagnosis (Alonso, Ursúa & Caperos, 2017:650; Miltea et al., 2015:9; Nikmat et al., 2015:115).

Institutionalisation is hard for the elderly as they are forced to move away from their familiar home environment and deal with the immense sense of loss and change. This transition is similarly traumatic for family caregivers, who often consider institutionalisation to be a last resort (Alonso et al., 2017:650; Carmen, 2013:1630). The gloomy reality exists that AD is a “neurodegenerative disease characterised by progressive cognitive decline leading to complete need for care within several years after clinical diagnosis” (Hampel et al., 2011:719). Due to the array of losses and setbacks experienced by individuals diagnosed with degenerative dementia, their physical needs require close observation and constant attention (Eliopoulos, 2014:449). As a result, spouses, or adult children are faced with the daunting decision of caring for their spouse or parent at home or placing them in an institution in which their specific needs are catered for.

1.2.4.2 Consequences of institutionalisation

Unfortunately, several studies have indicated that negative consequences such as depression, increased sense of loneliness and alienation follow institutionalisation (Nikmat et al., 2015:115; Runcan, 2012:109). Loneliness and depression are serious mental health concerns across the spectrum of residential care, from nursing homes to assisted and retirement living (Runcan, 2012:109; Theurer, Mortenson, Stone, Suto, Timonen & Rozanova, 2015:201). For PWD, the home environment can stimulate a sense of personhood, stability and normalcy in the face of discontinuity and disconnection often experienced because of several losses in the cognitive, functional and social domains of their lives, and leaving behind an environment that is familiar to the PWD is both traumatic and stressful (Aminzadeh, Dalziel, Molnar & Garcia, 2009:487; Runcan, 2012:110). However, Aminzadeh et al. (2009:487) continue to state that PWD are frequently faced with the reality of several housing transitions during the progression of their illness. As the disease progresses, it may be recommended that they relocate to a safer and more supportive living environment. Deciding to go the route of institutionalisation may therefore be one of the most complex decisions an adult child has to make.

1.3 THEORETICAL FRAMEWORK

In this study, every individual diagnosed with AD has a family in which they operate, and to establish the impact that an AD diagnosis has on the adult child and the family, the researcher will focus primarily on the Family Systems Theory. By making use of this theory, the researcher places herself outside of the family system as an observer of what is going on inside the system (Becvar & Becvar, 2014:69).

The source of Bavelas and Segal (1982) is a seminal source and the researcher regards the information as relevant concerning the family as a system. A family system (Bavelas & Segal, 1982:101-102), is “a special set of people with relationships between them; these relationships are established, maintained, and evidenced by the members communicating with each other”. Bavelas and Segal (1982:102) continue that insofar as family relationships endure, they form patterns over time, and this patterning over time is the core of a family system. These relationships and patterns ultimately make

the family system whole (Bavelas & Segal, 1982:102). Bavelas and Segal (1982:102) explain that according to the systems view it is necessary to focus overall (family) and to determine how the individual parts (individual members in the family) fit into the whole. Becvar and Becvar (2014:69) assert that by adopting the Family Systems Theory as a theoretical framework, one will be able to see people and events in the context of mutual interaction and mutual influence. Thus, “rather than examining individuals and elements in isolation, one looks to their relationship and how each interacts with and influences the other”.

No family functions as an isolated system. Boundaries are open to many interactions with other persons and environments (Bavelas & Segal, 1982:102). Becvar and Becvar (2014:70) state that from a systemic perspective, “we see every system influencing and being influenced by every other system and every individual influencing and being influenced by every other individual in the system”. In some cases, the family system may be described solely in terms of its present process (Bavelas & Segal, 1982:103), however, it is essential to note that the family system is ever changing. Because of the intensity of an AD diagnosis, the diagnosis can disrupt the very foundation of a family system. By not only focusing on the diagnosed older parent, but on the family system in which the older parent functions, the researcher will be able to construct a richer picture of the true impact that an AD diagnosis and the decision to institutionalise has on the adult child and the ill parent. By conducting her research from this backdrop, the researcher will further identify and discuss the difficulty faced by adult children in identifying a frail care facility in Namibia that offers the specialised services required to take care of their now demented parents.

1.4 RATIONALE AND PROBLEM STATEMENT

Dementia affects both the diagnosed person and the people closest to them. In comparison to the other chronic illnesses, the slow degeneration, severe dementia-related behaviour problems, and the knowing that it will only end when the patient passes away, largely makes dementia a more difficult disease for families to deal with (Sarafino & Smith, 2012:317). The decision to institutionalise the dementia patient is always grim and the caregiver often feels torn between the reality of a progressive

disease, family pressure as well as promises formerly made (Alonso et al., 2017:650; Carmen, 2013:1630).

The researcher is specifically interested in the experiences of adult children who had to make the difficult decision of placing their older parents diagnosed AD in an institution, their experiences in finding a care facility for their now demented parents in Namibia, and their experiences of the impact of the decision to institutionalise their parents had on the parent-child relationship. While this research study is done within a smaller context, it aims to explore and give a clearer picture of the subjective experiences of adult children in dealing with the changes brought about by an AD diagnosis, specifically relating to the impact of dementia on the relationship between the adult child and the older parent. The study will explore the health care options available to older parents, specifically limited to Namibia where there are two institutions for care of people diagnosed with this specific disease. The limited resources may make the decision to institutionalise an older parent even more difficult. This necessitates further research in the country specific context.

The research question that this study aims to answer is: What are the experiences of adult children, who made the decision to place their parents diagnosed with AD in the ADN Care Farm Namibia?

1.5 GOAL AND OBJECTIVES

The goal of this research study is to explore and describe the experiences of adult children, who made the decision to place their parents diagnosed with Alzheimer's disease (AD) in a dementia care clinic in Namibia.

The objectives of this study are to:

- Contextualise AD and the effect thereof on the individual and the family systems involved in the diagnosed individual's life.
- Explore and discuss the effect that an AD diagnosis of a parent has on the adult child.

- Within the context of the Family Systems Theory, identify and discuss the impact that dementia and AD has on the relationship between the adult child and the ill parent.
- Explore and describe the impact the decision to institutionalise parents with AD has on children.
- Identify and describe challenges faced by adult children in finding an institution, in Namibia, which will meet the specific and special needs of their older parents diagnosed with AD.
- Explore and discuss the need for awareness raising and education about dementia and AD to address the stigma attached to the disease.
- Draw conclusions and make recommendations, emanating from the research findings to service providers responsible for care management of older persons about resources available to family members of diagnosed older AD patients in Namibia.

1.6 RESEARCH APPROACH

For this study, the qualitative research approach is most applicable. Qualitative researchers aim to tap into the deeper, personal experiences of their respondents (Rubin & Babbie, 2013:40). Every individual is unique and understands and experiences life events differently, and as such qualitative researchers do not describe to one truth, but rather, to many truths (Streubert, 2011a:20). To report on the personal experiences of their respondents, qualitative researchers emphasise six essential characteristics in their research (Streubert, 2011a:20):

(1) a belief in multiple realities; (2) a commitment to identifying an approach to understanding that supports the phenomena studied; (3) a commitment to the participant's viewpoint; (4) the conduct of inquiry in a way that limits disruption of the natural context of the phenomena of interest; (5) acknowledged participation of the researcher in the research process; and (6) the reporting of the data in a literary style, rich with participant commentaries.

Creswell (2007:37-39), which is a seminal source, mentions that researchers, making use of the qualitative approach, attempt to develop a complex and holistic view of specific social phenomena. Qualitative researchers believe that there are always multiple truths (perspectives) to consider when fully trying to understand a situation

(Streubert, 2011a:20). In this study, the researcher was interested in the phenomenon of dementia, with a specific focus on the subjective experiences of adult children, living in Namibia, in dealing with the various life changes brought about by a dementia diagnosis in their older parents. Empirical research can improve the understanding of and compassion for people whose life experiences and cultural perspectives differ from one's own through "articulating their experiences and perspectives, including negative responses to generally effective intervention strategies" (Haight, 2010:102). To understand the true impact that the disease had on each individual respondent, the researcher immersed herself in the personal experiences of each respondent and aimed to understand the impact of the disease from everyone's perspective. AD is a universal disease, but everyone experiences and deals with this devastating disease in unique ways, and as such the qualitative research approach allowed the researcher to tap into these personal experiences of the respondents.

1.7 TYPE OF RESEARCH

The applied research perspective was most suitable for this study. In social work, evidence from empirical research is combined with professional understanding of "sociocultural context, together with the clients' beliefs, values, and behaviours as a guide to intervention" (Haight, 2010:101). Applied research is used when the researcher is interested in addressing a specific concern and is designed to offer practical and concrete solutions to existing problems in practice (Neuman, 2014:27; Sarantakos, 2005:10, Polit & Beck, 2006:18). Applied research aims at helping researchers accomplish tasks and is further aimed at solving specific policy problems (Fouché & De Vos, 2016:95). Neuman (2014:28) asserts that the three major types of applied research are evaluation research, action orientated research and social impact assessment. For this study, action orientated research is most applicable.

Through applying action research, which is "applied research in which the primary goal is to facilitate social change or bring about a value-orientated political-social goal" (Neuman, 2014:30), the researcher hoped to create more awareness around dementia and AD in Namibia. Action research "treats knowledge as a form of power" and it merges obtaining new knowledge with expending the knowledge to achieve a specific

purpose (Neuman, 2014:30). By focusing on the applied research perspective, the researcher hoped to magnify the absence of a frail care policy in Namibia.

1.8 RESEARCH DESIGN

In this study, the researcher made use of a phenomenological design. Phenomenology is a philosophical paradigm used for conducting qualitative research that emphasise people's subjective experiences and interpretations of the world (Rubin & Babbie, 2013:248). Phenomenology is an approach to thinking about people's life experiences (Polit & Beck, 2006:219). Phenomenological researchers ask: "What is the essence of this phenomenon as experienced by these people and what does it mean?", and thus phenomenologists investigate subjective phenomena in the belief that critical truths about reality are grounded in people's lived experiences (Polit & Beck, 2006:219). Buxton (2011:73) confirms the above by stating that phenomenology is a science with the purpose to describe specific phenomena, or the appearance of things, as lived experience.

An important phenomenological principle in qualitative research involves the word "understanding", and guided by this principle, qualitative researchers attempt to understand the people they observe from those people's own perspectives (Rubin & Babbie, 2013:248). The product of the research is a careful description of the conscious everyday experiences and social action of subjects, the lived experiences of everyday life are the central focus of a phenomenological inquiry and the main goal of phenomenology is to describe lived experience (Buxton, 2011:74; Streubert, 2011c:316).

1.9 RESEARCH METHODS

The researcher approached Mr. Berrie Holtzhausen, who she had met on more than one occasion, with the purpose of informing him of the intentions of her research, and to discuss the possible recruitment of research participants from the ADN Care Farm. Recruitment criteria included: adult child, male or female, of a parent who is living or lived with AD, and who is or was a resident at the ADN Care Farm. Dementia is an umbrella term used to describe diseases that cause irreversible permanent damage to

the brain (Alzheimer's Association, 2018b); and although there are many causes of dementia AD is the most common cause, and as such it was suggested that the researcher focus primarily on adult children who have parents living with AD.

A qualitative study is conducted to discover the nature of a person's personal and first-hand experiences regarding a specific phenomenon; and this approach is adopted when the researcher attempts to explore, discover, define, and comprehend what lies behind any phenomenon about which perhaps little is known (Cypress, 2015:356). Therefore, although the study population and sample size was small and limited to adult children whose parents are/were residents of the ADN Care Farm, the data collected from the participants was rich and gave the researcher a better understanding of what it is to have a parent living with AD from the personal experiences of each participant. The responses from all 11 (eleven) respondents answered the research question and assisted the researcher to shed a light on the need for greater awareness raising of dementia in Namibia. A qualitative health research approach is adopted with the purpose of exploring health and illness as they are "perceived by the people themselves rather than from the researcher's perspective" (Cypress, 2015:357); and therefore, although the research has had first-hand experience with an AD diagnoses in a family member, she wanted to understand the impact of the disease from other people's personal experiences and perceptions.

Each participant was asked to sign an informed consent form, giving the researcher permission to report on their personal experiences. Participants were informed that their personal details, such as their names and the names of their parents, would not be published. The researcher conducted in-depth one on one interviews with each participant; with the permission of the participants she used an audio recorder to record each interview; and once all the interviews were conducted, recordings were transcribed. The researcher sent each transcription to the respective participant to establish whether they recognised and agreed with the findings as transcribed by the researcher (Brink et al., 2014:172; Streubert, 2011b:48; Thomas, Nelson & Silverman, 2011:368).

In this section, although briefly, the researcher discussed the research approach adopted; the study population and sampling methods used to select participants; and the process of data collection and data analysis.

1.10 CHAPTER OUTLINE

Included in this research report is:

Chapter 1: Introduction to the research study

In this chapter the researcher introduces the reader to the theme of the study, the rationale for the study, the goal and objectives of the study as well as a brief overview of the research approach, type of research and research design and research methods which the researcher adopted for the study. Limitations of the study are addressed.

Chapter 2: The life cycle of the adult child and the older parent: A Family System's Perspective

In this chapter the researcher discusses the lifespan development of both the adult child (with specific focus on early and middle adulthood), and the older parent (late adulthood), and how the relationship between parent and child changes throughout the lifespan, with specific emphasis placed on the parent-child relationship in later life. The researcher further approached this chapter from a family systems perspective, with a specific focus on the impact that a dementia diagnosis and the decision to institutionalise has on the functioning of the family system.

Chapter 3: Alzheimer's disease care management in the Namibian context

The purpose of this chapter is to have an in-depth look into dementia, with a specific focus on dementia and AD in older adults. Dementia has been diagnosed in people younger than 50 years of age, but for this study, the researcher is interested only in those individuals aged 65 and older. The researcher further focuses on the specific and specialised care needs of older adults living with dementia, with a specific focus on the availability, affordability and accessibility of these services in Namibia.

Chapter 4: Research methodology

In this chapter, the researcher discusses the research methodology of the study.

Chapter 5: Empirical research

In this chapter, the researcher discusses the analysed data and compare the findings with literature.

Chapter 6: Summary, conclusions and recommendations

In this chapter, the researcher presents the key findings, conclusions and recommendations drawn from the empirical findings of the research study.

1.11 LIMITATIONS OF THE STUDY

The following limitations were identified:

- The study population and sample size selected were small and restricted to one care facility in Namibia. However, it would have been impossible for the researcher to identify and conduct interviews with every adult child in Namibia who has a parent living with AD. Although the study population was small, the data collected contained much needed information and answered the research question. This research provides a foundation for further research on the topic.
- Although the researcher intended to have an equal number of male and female participants, from the 11 (eleven) participants only three were males. The misconception exists that men are less likely to express their emotions; however, the three male participants all shared their personal emotions and perceptions.
- From the 11 (eleven) participants interviewed two were Coloured and nine were White; and all participants were able to afford placing their parents in a private care facility.
- The research study was conducted on a small scale, and although the researcher aimed to shed light on AD in the Namibian context, she only managed to report on a small number of cases which cannot be generalised to the entire Namibian

population. However, Mr. Berrie Holtzhausen, who founded ADN Namibia, has travelled across Namibia and has reported on his findings regarding stigma attached to the disease within the different Namibian cultures.

- All 11 (eleven) interviews were conducted in Afrikaans and the researcher had to translate the information, used in each theme, to English. Although she attempted to translate the interviews as accurately as possible, some emotions and experiences expressed by participants might have been lost in translation.

1.12 SUMMARY

In the introduction it was revealed that although population ageing is a victory of development, it brings about challenges in every sector of society and has global implications for health systems. People are living longer than ever before, and failing health often accompanies old age, which increases the demand for health care and long care services. There is a considerable rise in the number of people living with dementia globally, and there is a greater realization that public health measures will play an imperative role in the effort to guard world populations from cognitive impairment and dementia.

In the brief literature review, the researcher elaborated on the impact that a dementia and AD diagnosis has not only on the parent living with the disease, but also on their families and the community. AD has a profound impact on the adult child who, due to the progressiveness of the disease, had to make the difficult decision to place their parents in the ADN Care Facility. Placing a parent in a care facility is difficult for the adult child, but it involves a profound sense of loss for the parent as well. AD affects all members of a family and has an enormous impact on the functioning of the family system. Therefore, to understand the impact of AD on the family the researcher approached her study from a Family Systems point of view. This theoretical framework allowed the researcher to study and observe the adult child and older parent from outside the family system and assisted her to objectively report on the impact of the disease.

CHAPTER 2

THE LIFE CYCLE OF THE ADULT CHILD AND THE OLDER PARENT: A FAMILY SYSTEMS PERSPECTIVE

2.1 INTRODUCTION

On his enthronement, as the first black Archbishop to head the South Africa's Anglican Church, on the 7th of September 1986, Desmond Tutu said "You do not choose your family. They are God's gift to you, as you are to them" (South African History Online, 2011). Although families are not always perceived as a gift, the impact that families have on the "life span trajectories and life course experiences" of an individual (Antonucci & Wong, 2010:515) cannot be ignored nor disputed.

The family can be described as a multifaceted whole, made up of interrelated and intermingling parts; an ever-changing system of interconnected subsystems which function within other systems (Santrock, 2015:186; Sigelman & Rider, 2015:470). Although an entity, an individual's behaviour and actions need to be observed within the contexts of both the family and the larger culture, which are ever changing (McGoldrick & Shibusawa, 2016:378). The family is a "complex, integrated whole" in which individual family members are essentially co-dependent, exerting a constant and reciprocal influence on one another. Therefore, any individual family member is inseparably rooted in the greater family system and can never be entirely understood independent of the context of that system (Cox, 2010:95; McGoldrick & Shibusawa, 2016:378; Sutphin, McDonough & Schrenkel, 2013:506). Whether born into or adopted, functional or a little broken, the family plays a fundamental role throughout the separate phases of development. The family exists in some form or another in all societies and as one of the first human social institutions, families are created by human beings to have certain elementary and social needs met (Schwartz & Scott, 2010:2). A family consists of individuals who share a history and a future, it encompasses the entire emotional system of at least three, and as late four or even five generations, held together by blood, legal and/or historical ties (McGoldrick & Shibusawa, 2016:376).

The family life cycle progresses through many varied life paths and challenges unique to each family, and thus the conception that the family life cycle consists of an orderly progression through predictable life stages needs to be altered (Walsh, 2016:19). Sigelman and Rider (2015:471) state that changes in family membership, such as a parent dying, and changes in any person or relationship within the family, such as the relationship between the adult child and their now demented parent, affect the dynamics of the entire system. AD is one of the unpredictable, undesirable challenges that the families in this study have come face to face with; a diagnosis that has affected the dynamics of the entire family system and interconnected subsystems. The Alzheimer's Society (2014a:1) states the following:

Alzheimer's disease is the most common cause of dementia. The word dementia describes a set of symptoms that can include memory loss and difficulties with thinking, problem-solving or language. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease.

Based on the above explanation, the researcher will use both the term "dementia" and "AD" interchangeably throughout the study, based on the knowledge that AD is one of the most common causes of dementia.

In this chapter, the researcher will discuss the life span development of both the adult child (with specific focus on early and middle adulthood) and the older parent (late adulthood), and how the relationship between parent and child changes throughout the life cycle, with specific focus on the parent-child relationship in later life. The researcher will further approach this chapter from a family systems perspective with a specific focus on the impact that a dementia diagnosis and the decision to institutionalise has on the functioning of the family system.

2.2 UNDERSTANDING THE FAMILY SYSTEM

AD and other dementias not only have a profound impact on those who are diagnosed, but also on the people who are closest to them (Alzheimer's Society Canada, 2014; Alzheimer's Research UK, 2015:3); it is a "family disease" (Barr, Shaw & Chapman, 2016:35). To shed some light on the impact an AD diagnosis has on those closest to the diagnosed older parent, the researcher focused on the adult children of a group of

older persons living with AD. In this study, every individual diagnosed with AD has a family in which they operate, and to establish the impact that an AD diagnosis has on the adult child and their respective relationships with their older parent, the researcher primarily used the Family Systems Theory as theoretical framework. By making use of this theory, the researcher placed herself outside of the family system as an observer of what is going on inside of the system (Becvar & Becvar, 2014:69).

2.2.1 General Systems Theory

Systems theory originated from the work of the biologist Ludwig von Bertalanffy, and has its roots in “mathematics, biology and cybernetics and deals with the way that parts come together in larger wholes” (Beckett & Taylor, 2010:130). Sutphin et al. (2013:508) similarly defines a system as “a group of interacting and interdependent actors that function individually to form a complex whole”. The human body is a complex system made up of different cells, organs and tissue, and one cannot study the human body without studying each individual interacting part (Beckett & Taylor, 2010:130; Sigelman & Rider, 2015:470). Human beings are not merely systems within themselves, but each person forms part of larger interlocking and overlapping systems, such as their families, communities, organisations, and countries (Beckett & Taylor, 2010:130). Every system consists of subsystems and is itself a subsystem in even larger systems.

Family Systems Theory was birthed from General Systems Theory during the 1960s. Seeing that it relates to the social sciences, General Systems Theory “provides a link between the macro and micro levels of analysis and shows the interconnected relationship between the two levels” (Sutphin et al., 2013:506). One of the key features that the Family Systems Theory and General Systems Theory agree upon is the fact that the family system is regarded as a whole; and therefore, to understand how the family functions one should not solely focus on the individual parts (Sutphin et al., 2013:506), but rather look at the family system consisting of individual parts.

2.2.2 The Family Systems Theory

The sources of Bavelas and Segal (1982) and Broderick (1993) are seminal sources, and the information is relevant regarding the family as a system. A family system is “a

special set of people with relationships between them; these relationships are established, maintained, and evidenced by the members communicating with each other” (Bavelas & Segal, 1982:101-102). The Family Systems Theory conceptualises the family as a system, insinuating that like the human body, the family is a whole made up of interconnected parts, each of which affects and is affected by every other part, and each part contributes to the functioning of the whole (Beckett & Taylor, 2010:132; Sigelman & Rider, 2015:470; Sutphin et al., 2013:506;). Bavelas and Segal (1982:102) agree that according to the systems view it is necessary to focus overall (family) and to determine how the individual parts (individual members in the family) fit into the whole. Families are a distinctive subset of social systems and they are structured by an exclusive set of inter-gender and intergenerational relationships. Families are not merely affected by their internal boundaries and relations but are also influenced by the larger systems in which they function (Broderick, 1993:51; Sutphin et al., 2015:502). Bavelas and Segal (1982:102) continue that insofar as family relationships endure, they form patterns over time, which is the core of a family system. These relationships and patterns ultimately make the family system whole (Bavelas & Segal, 1982:102). The following implications exist when one considers the family to be a system (Beckett & Taylor, 2010:133):

- If families are systems, they have properties which are more than the sum of their parts, and we cannot entirely understand the behaviour of an individual in isolation, without looking at the system of which he/she is part.
- If they are comparable to biological systems, families will function to try to maintain a reasonably stable state. So, if a certain member of the family is consistently behaving in a certain way, this behaviour is likely to be serving the purpose of upholding a steady state, even if the family members themselves do not recognise this.
- Communication and feedback between the parts of the system (that is, the members of the family) are an imperative part of the functioning of the system. If we want to understand the family, we must observe the way members communicate with one another; and not just everyone in isolation.
- If one wants to understand the behaviour of an individual in the family, one typically understands it better in terms of circular causality, rather than linear causality. The behaviour of an individual is not merely the cause of other events in the family, or

simply the effect, but is linked to the rest of the family in a feedback loop – each one both controls and is controlled by one another.

- All systems are made up of smaller systems and are themselves part of larger systems.

Supporters of a systems perspective reason that when thinking about human problems and trying to resolve them, one often fails to bring about change because one is so focused on the individuals that one forgets to explore the system of which they are part (Beckett & Taylor, 2010:133). Walsh (2016:29) asserts that although family therapy approaches differ, they share a joint theoretical underpinning in systems theory, with basic assumptions about the mutual influence of family members. The Family Systems Theory, through the combination of ecological and developmental perspectives, is regarded as a “transactional system that functions in relation to its broader sociocultural context and evolves over the multigenerational family life cycle” (Walsh, 2016:29). Walsh (2016:29) continues by stating that:

...the systems paradigm advanced conceptualization of the family from a deterministic linear, casual view, focused on parent-child dyadic bonds, to the recognition of multiple, recursive influences within and beyond the family that shape individual and family functioning through ongoing transactions over the life course and across the generations.

Considering Walsh’s view of the systems paradigm, it is easy to comprehend how an Alzheimer’s diagnoses in a parent not only has a devastating impact on the diagnosed individual, but the devastation spreads and is experienced by the entire family system. By adopting the Family Systems Theory as a theoretical framework, one will be able to see people and events in the context of mutual interaction and mutual influence; and thus, “rather than examining individuals and elements in isolation, one looks to their relationship and how each interacts with and influences the other” (Becvar & Becvar, 2014:69).

Broderick (1993:37) states that the family can be regarded as an “open, ongoing, goal-seeking, self-regulating, social system”, and that it shares the features of all such systems. Whilst it shares features with other social systems, it is set apart by certain features such as its distinctive structuring of gender and generation (Broderick,

1993:37). Additionally, each individual system is moulded by its own “particular structural features, the psychobiological characteristics of its individual members, and its sociocultural and historic position in its larger environment” (Broderick, 1993:37).

Although Broderick (1993:37) describes a system as open and ongoing, he asserts that this does not suggest that the family has no boundaries between itself and its environment, but instead it suggests that only energy, matter and information flow back and forth across these boundaries. Beckett and Taylor (2010:131) concur with the above by stating that living systems, such as the family system, are typically open systems; and although these systems have semi-permeable boundaries, they still manage to maintain some sort of equilibrium with the outside world. Broderick (1993:37) further stresses that like all other systems, the family is involved in changes not only internal to itself, but also in relation to its environment. Sigelman and Rider (2015:471) agree with Broderick’s (1993:37) argument by stating that the family is also a system within other systems; it does not exist in a vacuum (Sigelman & Rider, 2015:471) and it does not function in isolation. Boundaries are open to many interactions with other persons and environments (Bavelas & Segal, 1982:102). Becvar and Becvar (2014:70) state that from a systemic perspective, “we see every system influencing and being influenced by every other system and every individual influencing and being influenced by every other individual in the system”.

Family systems share the common attributes of all living systems, namely that they are “open, ongoing, goal-seeking, and self-regulating”, but contrast to any other type of system, their component parts are self-aware, self-directed and independent bodies (Broderick, 1993:46). In some cases, the family system may be described solely in terms of its present process (Bavelas & Segal, 1982:103), but as stipulated by Hooper (2007:220) the family system is ever changing. The family system is not merely embedded within systems, and it is not only a developing system, but the world in which it is fixed is also ever changing (Sigelman & Rider, 2015:472).

As stated earlier, changes within the family unsettle the dynamics of the entire system (Sigelman & Rider, 2015:471) with many pressures in family life being produced by greater forces in the world around them (Walsh, 2016:20); and thus, successful events, environmental situations, and difficulties of an individual member touch the whole

family as a functional unit, with consequences for all members and their relationships (Walsh, 2016:29). Horizontal and vertical stressors are part of every family system. Horizontal stressors refer to challenges arising by the passing of time and includes both predictable events such as the birth of a child, and unpredictable events such as illness (Beckett & Taylor, 2010:135). Some of these events are central to some families' experience but completely alien to others (Beckett & Taylor, 2010:135), for example: although all families eventually come face to face with an ill, old and frail family member, not all families will face an old family member deteriorating before their eyes due to a dementia diagnosis. Illness, disability, and death are universal experiences in families, and the question is not "if" a family will face these issues, but instead "when" and "for how long" the family will have to face these realities (Rolland, 2016:452). AD is a reality faced by an increasing number of families (Andreakou, Papadopoulos, Panagiotakos & Niakas, 2016:1). Barr et al. (2016:35) highlight the grim reality of AD in that it severely challenges relationships within the family and has the potential to totally ruin them.

From a system's perspective, each developmental stage – birth, adolescence, marriage, divorce, remarriage, retirement, and death - affects the entire family and not merely the individual members of the family (Beckett & Taylor, 2010:138). When a parent grows old and frail and cannot cope with daily life on their own, it poses challenges for both the spouses and the children as well (Beckett & Taylor, 2010:138). Because of the intensity of an AD diagnosis, the diagnosis can disrupt the very foundation of a family system. Once an AD diagnosis is made family members are often forced to take on different responsibilities, sometimes sons and daughters of a parent with dementia become caregivers; husbands and wives see their roles change from partner to primary caregiver, and as AD progresses, family members may find the changing roles increasingly difficult to accept (Alzheimer's Society Canada, 2014). When parents become frail and dependent on family members for care, the adjustment involved for the whole family system is significant and is likely to bring up old troubles from the past (Beckett & Taylor, 2010:142). Aside from their own responsibilities, caregivers are often forced to take over the everyday tasks of their loved ones, like chores or personal hygiene, and they may feel burdened and overwhelmed. This could lead to the person withdrawing or avoiding family activities. Although it is a universal

disease and the situation that they are faced with is the same, people react differently (Alzheimer's Society Canada, 2014).

The disconnecting effects of dementia are not restricted to husbands and wives; ever so often adult children, extended family members and even friends also pull away from and cut ties with the person diagnosed with AD (Barr et al., 2016:46). Each system is unique, and as a result, in many families Alzheimer's caregiving nurtures strength and support, whilst in other families, it tears relationships apart (Alzheimer's Association, 2017:2). Every facet of a person's life and relationship with others is eventually impacted by this disease (Barr et al., 2016:102), and thus by focusing not only on the diagnosed older parent, but on the family system in which the older parent functions, the researcher will be able to portray a richer picture of the true impact that an AD diagnosis and the decision to institutionalise, has on the adult child of the ill parent. By conducting her research from this backdrop, the researcher will further identify and discuss the difficulty faced by adult children in identifying a frail care facility in Namibia that offers the specialized services required to take care of their now demented parent.

2.3 LIFE SPAN DEVELOPMENT

Life span refers to the physical and cognitive changes in an individual from birth to death. In the context of this research, the focus will be on early, middle and late adulthood.

2.3.1 The adult child: early and middle adulthood

In this study, the ages of the participants fall within the development phase of both early and middle adulthood. Santrock (2015:14) differentiates between early and middle adulthood. Early adulthood is "the development period that begins in the early twenties and lasts through the thirties"; and middle adulthood is "the development period from approximately 40 to about 60 years of age." Considering the above, for this research study, the term 'adult child' will thus refer to any person between the age of 20 and 59 years who is the biological child of a parent with AD. To allow the researcher to explore the life of the adult child and the impact that an AD diagnosis has had on the relationship between the adult child and the older parent, attention will

be given to both early and middle adulthood, and the important characteristics of each of these developmental phases will be elaborated on to bring the theory into context.

2.3.2 The adult child: the establishment of self and development of others

The life-span development perspective perceives human development as a life-long process, and that experiences and events that occurred in earlier parts of the life course has a direct impact on how an individual adapts in their later years (Cho, Martin & Poon, 2015:133). Life-span developmental psychology involves (Baltes, 1987:611):

...the study of constancy and change in behaviour throughout the life course (ontogenesis), from conception to death. The goal is to obtain knowledge about general principles of life-long development, about inter individual differences and similarities in development, as well as about the degree and conditions of individual plasticity or modifiability of development.

The life span development theory looks at human development across the whole of life and does not only focus on childhood development (Beckett & Taylor, 2010:114). Baltes (1987:613) identified seven main principles of the lifespan perspective:

- Development is a lifelong process.
- Development is multidimensional and multidirectional.
- The process shows plasticity – that is, it can be affected and changed by life experience and circumstances.
- It involves both gains and losses.
- It is an interactive process between the individual and their environment.
- It is culturally and historically embedded.
- It is a multidisciplinary field of study.

Baltes (1987) asserts that development is a lifelong process which involves interaction with systems in and around the individual and can be altered by personal experiences and circumstances. Each development phase has its own milestones, challenges and victories, and it is therefore important that the researcher reflects on the developmental

phases of the adult children to understand how an AD diagnosis effects or disrupts the life phase which they find themselves in.

Development from infant to adult is systematic, characterised by changes that are methodical, patterned and rather stable (Sigelman & Rider, 2015: 4). From conception to death, human development through each life phase, is characterised by changes in “biological, cognitive and socio-emotional dimensions”, which encompass gains, losses, neutral changes, and stabilities (Santrock, 2015:3; Sigelman & Rider, 2015:4). As the family transitions through the various phases of the life cycle, relationships with parents, siblings and other family members change, boundaries shift, psychological distance among members change, and roles within the subsystem are constantly being redefined (McGoldrick & Shibusawa, 2016:36). The family system is the primary developmental context of childhood (Jobe-Shields, Andrews, Parra & Williams, 2015:432), and it remains a key facet in development across the lifespan of an individual.

2.3.2.1 Early adulthood

Entry into adulthood does not mean an individual has reached the end of development. On the contrary, entry into adulthood is accompanied by the insight that development is a continuous process (Sigelman & Rider, 2015:348) tainted with obstacles and victories alike. When individuals step into adulthood, they often take with them a better understanding of the self and the world in which they now operate (Sigelman & Rider, 2015:348). Early adulthood refers to the development period that begins in the early twenties and lasts throughout the late thirties and even early forties (Santrock, 2015:14; Sigelman & Rider, 2015:5). Early adulthood is a time for work and a time for love, a phase that leaves little time for anything else (Santrock, 2015:399), a distinct transitional phase branded by amplified autonomy and exploration of identity (Guan & Fuligni, 2015:286), a time centred on the self, its desires and personal development.

This development phase is mainly centred around the consideration of vocational careers, launching and advancing careers chosen, striving towards personal and economic independence, establishing one’s role as an adult, and for many it is a time for selecting a mate, starting a family and rearing children (Santrock, 2015:14;

Sigelman & Rider, 2015:5, 356). After the rather unsettled 20's and decision-making 30's, adults often reach the top of their career ladder in their 40's, and this is a time marked with major responsibilities and defining oneself in terms of the careers chosen (Sigelman & Rider, 2015:356). Early adulthood is a time of self-establishment, self-realization, and self-enrichment, a time focused on establishing oneself and pursuing goals and dreams.

2.3.2.2 Middle adulthood

The age of 40 is often regarded as an indicator of mid-life and a focal point in development. Middle adulthood is the time where an individual realises that the time stretched behind is more than the time stretched before, and although reluctantly, the individual begins to evaluate what was and is important (Santrock, 2015:456). Adults who find themselves transitioning into middle adulthood begin to reflect on what they did with the time they had, and they look towards the future in hope to accomplish the goals they set for themselves when they were younger (Santrock, 2015:458). Striving to achieve a sense of accomplishment about their lives, with the aim to help create a positive change in others, mid-lifers struggle with “generativity versus stagnation” (Foster & Levitov, 2012:67), hoping that what they have done and who they have become is good enough. During middle adulthood “who we have been forms who we will be”, and for many, middle adulthood is a foggy place tainted with regrets and ‘what ifs’ (Santrock, 2015:456). Although middle adulthood is often anticipated as a time of deterioration, Santrock (2015:459) asserts that just like all the other phases of human development, there will always be both positive and negative features to be embraced.

For most people, middle adulthood is a time marked by declining physical skills and growing responsibility during which individuals attempt to impart something meaningful to the next generation; and when career satisfaction is obtained and maintained (Beckett & Taylor, 2010:124; Santrock, 2015:460). Middle adulthood is often the time during which individuals strive to find a balance between work and relationship responsibilities, whilst coming to grips with changes in their physical and psychological health (Santrock, 2015:460). Adults in midlife play significant roles not only in the lives of their children and spouses, but also in the lives of the older generation, such as their parents. Midlife is a phase for launching children into the adult world, a time where

adult children boomerang back into the home, a time where children are married off and grandchildren are born, and every so often a time during which an older or frail parent needs to be taken care of (Kunz, 2013:170; Santrock, 2015:502).

As in other life phases, middle-aged adults make important life choices such as choosing what to do, determining how to invest their time and resources, and evaluating their lives and relationships (Santrock, 2015:460). Midlife involves a restructuring of family relationships as children launch and grandparents age, and this is often a difficult phase for many people, especially when they must care for multiple generations (Kunz, 2013:170; Murphy, Nalbone, Wetchler & Edwards, 2015:238). During this life phase, most people have settled down with their families, established themselves in their careers, and now must invest in things and in people that will make positive and lasting contributions to the next phase of their lives. The mid-life transition can be summarised as a time of life when it becomes necessary to renounce an identity as 'young', and like all other transitions there is most likely to be a hint of grief and denial involved in this (Beckett & Taylor, 2010:124).

It was only during the late 20th century that middle age was a period during which the nest is emptied of children and this distinct life phase arose as 20th century parents began to bear fewer children and lived long enough to see their children grow up and leave home (Sigelman & Rider, 2015:8). In both young and middle adulthood difficulties exist that adults will be forced to face. However, middle adulthood is marked by specific challenges such as adults having difficulties with their adolescent children and facing the reality that they might need to care for older relatives (Beckett & Taylor, 2010:125). Sigelman and Rider (2015:8) assert that although middle age has occasionally been considered as a time of crises and at times a period of barely any transformation, it is now understood to be a period of good health, cognitive functioning, unwavering relationships, numerous responsibilities, and extraordinary fulfilment for most people.

2.3.3 The adult child: finding the balance

As previously stated, for this study the adult child refers to individuals who are either in the development phase of early or middle adulthood, namely individuals who are

between twenty to fifty-nine years of age (Santrock, 2015:14). Transitions into adulthood, such as leaving school, entering the workforce, choosing a spouse, having a child, or caring for an older parent are transitions which encompass some degree of choice, but these transitions do not always occur in order (Cowan & Cowan, 2016:429). As the different transitions emerge, such as becoming an adult or growing old, shifts in the definition of “who we are and who we will become” occur; roles within the family change with transition through the different development phases, and ultimately “a shift in one’s inner world and identity and a reorganization of major life roles are almost inevitable accompanied by disequilibrium in one’s central relationships inside and outside the family” (Cowan & Cowan, 2016:430).

Taking into consideration the systems’ viewpoint, there are consequences all through the family system when an individual or a couple struggle with major life changes (Cowan & Cowan, 2016:430), such as an AD diagnosis in an older parent. An AD diagnosis often causes a change in the roles of different family members, as the adult children or spouses suddenly find themselves in the roles that they did not envision such as caregiver or advisor, and transitions such as these threaten to disrupt the normality within the family (Cowan & Cowan, 2016:430). In events such as this, the adult child’s usual resistance to these sudden changes may start to decline, and to survive or cope with the new reality, an openness to innovative ways start to emerge (Cowan & Cowan, 2016:430). To find the balance between having their own lives, caring for their own children and their own spouses, establishing and thriving in their careers, and taking into consideration their own mental and physical health, the adult children may be faced with the dreadful decision of placing their now demented and frail parent in an institution. Whether emerging into adulthood or being established in midlife, the adult child has dreams, goals and a life of his or her own.

2.4 THE OLDER ADULT: LATE ADULTHOOD

Population aging is progressing rapidly in both industrialised and developing countries (Chan, 2012:3; UN, 2017a:9; Von Humboldt & Leal, 2014:108). With individuals living longer, the quality of that longer life becomes a vital concern for both individual and social well-being (Von Humboldt, 2014:108). As the global number of older persons continues to grow, innovative approaches that focus on aging well, should be

developed for the elderly to ensure that their quality of life and dignity be promoted and safeguarded (Von Humboldt, 2014:108). Aging consists of “biological, psychological, and social dimensions” (Tiedt, 2016:72), and as adults reach late adulthood, they are more than likely to face physical, mental and social challenges within these dimensions (Bishop, 2014:7; Von Humboldt, 2014:108). The experiences acquired over their life time, ways in dealing with the environment, economic and social resources, relationships, and support systems will have an impact on how they deal with these challenges and can further profoundly influence their longevity and well-being (Von Humboldt, 2014:108).

2.4.1 Old age: then and now

Age is socially constructed, only a rough indicator of development status and given ages are only approximate (Kunz, 2013: 171; Sigelman & Rider, 2015:5). However, for this study, late adulthood is best conceptualised as the “development period that begins during the sixties or seventies and lasts until death” (Santrock, 2015:14).

Even at the beginning of documented history, only a few of people survived to old age (Carstensen & Fried, 2012:15), and it was not until the 20th century that society came to define old age as a time of retirement. Since not many people lived long enough to be classified as “old” in earlier eras, the ones who did reach old age were not as healthy as old people today, and those who did survive old age literally worked until they passed away (Sigelman & Rider, 2015:8). Sigelman and Rider (2015:8) further state that it was only during the last half of the 20th century that working adults began to retire in their 60’s with more years of life to look forward to. This was all due to the introduction of social security, pensions, Medicare, and other support programs. Improvements in standards of living and health, for example, have meant that today’s 65-year olds are not as old physically, cognitively, or psychosocially as 65-year olds were a few decades ago (Sigelman & Rider, 2015:5). In today’s rapidly ageing society, older adults remain healthy and happy well into their 70s. They find new meaning and fulfilment in novel pursuits and they often become actively involved with friends, family and especially grandchildren (Walsh, 2016:18).

Population ageing has become an observable fact not to be ignored, with one in nine persons in the world aged 60 years or over, projected to increase to one in five by 2050 (Osoimehin, 2012:11). In a report published by the United Nations, 901 million people over the age of 60 were recorded in 2015, which made up 12% of the global population; and this figure is expected to almost double, reaching 22% by 2050 (UN, 2015:7). In addition, it is projected that by the year 2030 the number of older persons in the world will be 1.4 billion and 2.1 billion by 2050, and that it could further rise to over 3.2 billion by 2100; and “in the short-to-medium term, higher numbers of older population are inevitable, given that the relevant cohorts are already alive” (UN, 2015:7).

A key concern for both developed and developing countries is how to deal with the challenges of an increasing elderly population during a period when traditional family support systems for elderly members are under attack from various directions (Schwartz & Scott, 2010:402). Although population ageing is a victory of development, it also brings about social, economic and cultural challenges to individuals, families, societies and the global community (United Nations Population Fund & HelpAge International, 2012:12). Walsh (2016:18) asserts that the fastest growing age group is adults over the age of 85, and they are the most vulnerable, with nearly half likely to be affected by AD.

2.4.2 Old age: what was and is to come

Ageing is a multifaceted phenomenon, which is hard to define at its various levels, i.e., “molecular, cellular, physiological and psycho-social”; ageing can be conceptualized as a process of increasing deficits, occurring in different individuals in different ways, with a “variety of rates for different organ systems, depending on the interplay of intrinsic and extrinsic” (Fulop, Larbi, Witkowski, McElhaney, Loeb, Mitnitski & Pawelec, 2010:548). Everyone wishes to age successfully, yet successful ageing is defined differently among individuals (Sigelman & Rider, 2015:161). Ageing has been observed through many lenses all through history, and over the last 50 years the definition of successful ageing has progressed from initial theories of activity and disconnection to theoretical approaches with a more direct focus (Martin, Kelly, Kahana, Kahana, Willcox, Willcox & Poon, 2015:21). Psychologist Carol Ryff believed that there are certain factors that ensure successful ageing, and that with these factors in mind it is

possible to age gracefully despite difficulties faced in families, close relationships, work and declining physical abilities (Middleton, Nicolson & O'Neill, 2013:2). The factors for successful ageing, as suggested by Ryff (1995), are:

- Self-acceptance.
- Positive relationships with others.
- Personal freedom.
- Control over one's environment.
- A purpose in life.
- Continued personal growth.

Rowe and Kahn's (1998) successful ageing concept contributed a great deal to challenge ageist attitudes and change the perception of successful ageing, and as such the researcher considers this an important source. Rowe and Kahn (1998:11) assert that there are countless misconceptions about old age such as old age is accompanied by sickness and disability, the elderly are not able to learn new things, older persons are unable to make lifestyle changes that would matter to physical and cognitive health at that point in life, and that all old people are dependent on others to meet their basic care needs. They are of the opinion that old people "are depicted as a figurative ball and chain holding back an otherwise spry collective society" (Rowe & Kahn, 1998:12). Furthermore, Rowe and Kahn (1998:40) agree with Carol Ryff's view of successful ageing to a certain extent as they define successful ageing as: "(a) the avoidance of disease and disability; (b) maintaining high levels of mental and physical function; and (c) active engagement with life, which revolves around "relationships with other people, and behaviour that is productive". Peterson and Martin (2014:10) make a valid point by stating that aging can be successful even though it is often regarded as a negative process, and:

The subjective experience of aging is not a straightforwardly linear event, especially within the changing social and political contexts that constitute a life course. Success is a matter of perception. That successful aging should include more subjective perceptions rather than only objective, mostly health-related criteria, has been mentioned by recent contributions to the successful aging literature.

To some, optimal ageing means being free of diseases, while to others, successful ageing is equated to being as independent as possible and pursuing a lifestyle that makes them feel satisfied (Sigelman & Rider, 2015:161). While the aging process is an unavoidable part of life and something all human beings share (Middleton et al., 2013:59; Howe, 2015:77), ageist attitudes may make the transition to older adulthood a process to be feared and eluded (Molden & Maxfield, 2017:29). Sigelman and Rider (2015:151) assert that although there are many dreaded changes that accompany old age, ageing should not only be equated to loss and decline. For some older adults a long-lived life is a blessing, while to others it may feel like a curse. Whether a blessing or a curse, the reality is that with advanced old age comes a steady acceleration and manifestation of many age-associated changes such as sensory deterioration, overall cognitive slowing, reduced functional mobility and social loss via death (Bishop, 2014:7). Ageism is an adverse stereotype; a belief or attitude that can and should be altered through education and awareness raising (Calasanti, 2016:1094).

The human body consists of several interconnected parts, as changes in one area of the body creates a ripple effect throughout the rest of the system (Sigelman & Rider, 2015:5). Aging does not only refer to biological aging, instead it speaks to a range of “physical, cognitive, and psychosocial changes”, which are positive and negative, in the developed being (Sigelman & Rider, 2015:5). Chronological aging is related to an increased risk of chronic disorders and diseases such as “cognitive impairment, cardiovascular disease, and metabolic syndrome”; and owing to prolonged life expectancy, age-related diseases have increased at frightening proportions in recent decades (Bherer, Erickson & Liu-Ambrose, 2013:1; Kunz, 2013:176). Old age is often initially attributed to changes in the physical appearance and functioning of an individual. Although physical feebleness and poor health are not a guaranteed part of ageing, some physical decline does accompany old age, and as later life progresses the occurrence of disability becomes higher (Beckett & Taylor, 2010:179). Fulop et al. (2010:549) similarly assert that although aging does predispose the elderly to frailty, not all older persons are guaranteed to be frail and dependent.

2.4.2.1 Physical changes and old age

Physical ageing is not something that happens all at once. It is a process that occurs slowly and steadily across the life span (Sigelman & Rider, 2015:152; Tiedt, 2015:72). Changes in physical appearance and health start during middle age, but these changes become more pronounced and have a more significant effect by the time old age is reached (Middleton et al., 2013:60; Santrock, 2015:522; Sigelman & Rider, 2015:152). While many physical abilities decline in the mid-thirties, the changes are not evident until many years later (Passer, Smith, Holt, Bremner, Sutherland & Vliek, 2009:555). As the human body ages, it deteriorates (Middleton et al., 2013:60). Old age is accompanied by slower movement, and older adults walk and move more slowly than their younger counterparts (Santrock, 2015:522; Sigelman & Rider, 2015:156). Although movement may seem like a futile aspect in late adulthood, Santrock (2015:522) stresses that adequate mobility is an imperative part of maintaining an autonomous and active lifestyle during old age.

The 20th century brought improvements in science and medication that has led to people living longer and healthier lives. However, science still has its limits and the inevitable happens as human bodies do not regenerate (Howe, 2015:15). Several facets of physical functioning appear to decline over the adult years in individuals (Middleton et al., 2013:60; Sigelman & Rider, 2015:157). One of these facets is one's susceptibility to disease or illness (Kunz, 2013:176). Older adults are likely to have some impairment or suffer from some or other chronic disease, such as arthritis or heart disease (Santrock, 2015:527; Sigelman & Rider, 2015:157). The possibility exists that disease, rather than aging, accounts for several declines in functioning in later life; and since many older people experience both aging and disease, it is challenging to separate the effects of the two (Sigelman & Rider, 2015:157). Although aging and disease are distinct, increased susceptibility to illness is an imperative part of normal aging (Sigelman & Rider, 2015:157). However, even during frailty and illness, many adults over the age of 65, who have a physical impairment, can perform everyday activities (Santrock, 2015:527). In the phase of late adulthood there are significant adjustments that need to be made by all older persons (Middleton et al., 2013:60), and Sigelman and Rider (2015:163) assert that although there are individual differences in

the physical functioning of older adults, negative stereotypes about ageing may cause many older adults to negatively interpret the natural changes that accompany aging.

2.4.2.2 Cognitive changes and old age

Cognitive functioning is a key facet of successful aging and while cognitive decline is common in older adults, all people experience these changes in individual and different ways (Bourassa, Memel, Woolverton & Sbarra, 2017:133). Many people have negative perceptions and expectations of old age, one of these being that aging means losing brain cells and ultimately becoming “senile” (Sigelman & Rider, 2015:152). The human brain, which is the most complex organ in the body and nervous system is always active with billions of electrical and chemical signals traveling from one neuron to the next (Middleton et al., 2013:2). Throughout a person’s lifespan, from conception to death, the structure of the brain is continuously changing, which means that normal aging, free from dementia, is associated with structural brain changes (Fjell & Walhovd, 2010:187), something that happens to the brain of every individual. As people grow older and slower physically, their brain functions also slow down; the way their physical functions change over time mirrors the way their cognitive function changes as well (Summers, 2016:3). Bishop (2014:7) asserts that living a remarkably long time and preserving an optimistic mind-set is not easy; and according to him, well-being in old age is an ironic experience. While many “old-old (ages 90 and older) adults” continue to feel happy, for many “emotional contentment may mask an underlying dissatisfaction with one's quality of life, which is further intensified by psychological symptoms including fatigue, anxiety, depressive affect, grief and apathy” (Bishop, 2014:7).

It is true that, with old age, many people develop mental health problems or conditions, such as depression, dementia or memory loss, but it is important to note that these mental health problems are not an inevitable part of old age (Mental Health Foundation, 2016:2). Hudson (2012:735) supports this by stating that several researchers have come to the fore in recent years who all found that there are dramatic declines in the occurrence of mental illness over the adult years. These discoveries do in fact challenge former expectations that manifestation of mental illness would instead increase with age, particularly given the well-documented deteriorations in physical

and cognitive functioning among several elderly persons. Mental health is significant to the totality of one's health (Barker, 2013:123), however, mental health is more than just the absence of symptoms of distress; it includes the affirmative experience of self, self-esteem and optimism, the ability to sustain relationships and resilience (Regan, 2016:8). Thus, the fear of old age cannot merely be based on the presumption that senility is inevitable. Even with a mental health condition, active ageing is achievable.

While most facets of memory deteriorate during late adulthood, Santrock (2015:545) states it is imperative to realise not all aspects of memory decline, and essentially, cognitive declines start to occur at different ages and rates for different people (Passer et al., 2009:559). The reality is that older adults do display poorer memory performance in some situations than compared to their younger counterparts, however, significant memory loss is not likely among healthy older adults (Howe, 2015:86; Sigelman & Rider, 2015:253). Successful ageing does not mean that changes in memory are eliminated (Santrock, 2015:545), but these changes are often minor and can be eluded or lessened by remaining physically and mentally active (Sigelman & Rider, 2015:253). Just like other parts of the body, the brain deteriorates in later adulthood (Middleton et al., 2013:60; Passer et al., 2009:555). While decline in memory is a normal part of ageing, Sigelman and Rider (2015:253) assert that families and professionals ought to be on the lookout for older adults who show noticeable declines in their memory performance, as this may be an indication that they are experiencing mild cognitive impairment and may eventually develop AD and impaired memory. Passer et al. (2009:557) state that during adulthood, information-processing abilities commonly tend to decline, but the age at which they start to decline varies from person to person.

Schwartz and Scott (2010:417) purport that chronic conditions, illness and injury can have a significant impact on the mental health of the elderly, and could lead to depression and dementia, which are two of the most common mental health problems experienced by the elderly. Dementia is one of the mental health problems that is becoming more common among the elderly. However, Souter (2015:47, 49) asserts that it is important to note that dementia is not a normal part of ageing, and although it is more common with increasing age, dementia is not the result of increasing age. From a medical point of view, dementia is the consequence of accumulating "lesions that only after decades overcome the ability of the brain to compensate for neuronal

damage”, and not merely an exaggeration of normal aging (Teipel, 2013:27). When the brain is injured by degenerative disorders such as dementia, disturbances in cognitive functioning are more likely to manifest (Middleton et al., 2013:8). It takes decades for the underlying disease to clinically manifest itself, therefore dementia is age-associated; and in various cases the brain can compensate for the accumulated damage over a long period of time (Teipel, 2013:27). Dementia is associated with old age but is not a normal part of ageing. The researcher will discuss dementia and the impact on the diagnosed individual in more detail in the next chapter.

2.4.3 Old age: the self and significant others

John Bowlby’s (1982) attachment theory describes how an emotional connection develops between an infant and its mother, as the attachment figure, to guarantee the child’s continued survival, growth, and development, and how this main attachment is supplemented or substituted by attachments to other individuals (Cicirelli, 2010:191). Attachment, according to Bowlby’s theory, can be defined as “a strong affectional tie that binds a person to an intimate companion” (Sigelman & Rider, 2015:440). Throughout the life span, the objects of one’s attachments are people that are special and irreplaceable, people who one wants to retain relationships with, and who makes one feel safe (Sigelman & Rider, 2015:440). It has been more than 40 years since John Bowlby suggested that the attachment system is influential from birth to death (Chopik, Edelstein & Fraley, 2012:171). Researchers recognised several significant links between individual differences in attachment and behaviour, emotion and cognition in close relationships, however very little consideration has been given to the attachment, and the importance of attachment figures, in old age (Chopik et al., 2012:171; Cicirelli, 2010:191). While it is an area that has not enjoyed much attention, several attachment related phenomena can transpire after young adulthood (Chopik et al., 2012:171). It is important to note that old age presents many difficulties in attachment relationships (Cicirelli, 2010:192). Relationships remain an essential aspect throughout the lifespan.

2.4.3.1 The importance of relationships with others

A significant characteristic of human society is that individual lives are entwined through social relationships (Yang, Boen, Gerken, Li, Schorpp & Harris, 2016:578).

Everyone maintains several interpersonal relationships on a day-to-day basis with some relationships momentary, such as a once-off interaction with the petrol attendant, while other relationships are more substantial (Van Deventer & Mojapelo-Batka, 2013:162). Human beings do not grow and develop in isolation; people form parts of larger systems and it is within that context that individuals develop and establish their identity (Beckett & Taylor, 2010:129). From childhood to old age, healthy friendships and family relationships can provide cognitive and emotional resources (Santrock, 2015:326), which are important for social development and overall wellbeing. Tough, Siegrist and Fekete (2017:2) assert that studies have shown that continual positive exchange with one's immediate social environment (e.g. family, friends and work life) exerts positive effects on health and wellbeing. On the other hand, social isolation or absence of close social bonds is connected to pitiable health and greater mortality risk. Quality relationships significantly contribute to overall wellbeing throughout the lifespan, and it appears to specifically add to the wellbeing of the elderly.

2.4.3.2 Relationships and old age

The making and maintaining of relationships are essential during old age; however, the reality exists that, although maintaining social relationships is vital in combating loneliness, as people age their peer relationships become fewer and fewer (Middleton et al., 2013:57). Although social network size appears to decrease with age, studies have shown that the interactions that older people have, with those who remain in their network, are more fulfilling and that they experience more positive emotions when interacting with their social partners than do younger adults (Luong, Charles & Fingerman, 2011:10). Older adults' attachments and how they maintain their relationships with these attachment figures are impacted by relational and environmental factors; and although family members remain key attachment figures throughout the life cycle, death or severe impairment often leads to older people directing their primary attachment needs, like they had with a parent or spouse, to other people they have close relationships with, such as an adult child or caregiver (Cicirelli, 2010:192; Lee & Montelongo, 2016:201). Cicirelli (2010:192) states that older adults with failing health may depend on continuous help from others such as caregivers or other medical professionals, and as a result they may develop attachment relationships

with these people who visit them often and put their faith in them to satisfy their need for comfort and emotional support.

Relationships are essential in all people's lives, and the quality of the relationship directly influences both the physical and mental health of an individual (Lee & Montelongo, 2016:200). Looking after physical and mental health is one of the main elements of successful aging and quality of life (Morack, Infurna, Ram & Gerstorf, 2013:475). When one transitions into late adulthood, it is important to maintain healthy social connections as this plays a vital role in protecting health in older adulthood (Yang et al., 2016:582). Old age has been marked by many losses, and as such emotional support has been identified as an element that can offer comfort during this life phase (Lee & Montelongo, 2016:200). Although older adults are less likely to forge new friendships, they do have a few close friends who act as their social support, and social support, or the lack thereof, has been proven to have a direct impact on the mental and physical health of older adults (Santrock, 2015:583,584). Conserving a good personal network is essential for older adults as having a considerable number of personal relationships decreases the risk of social isolation (Broese van Groenou, Hoogendijk & van Tilburg, 2012:275). Despite the importance of personal relationships, and although it has been proven that personal networks provide the support required to secure self-sufficiency and well-being in old age, the decline in network size and social contact as people age is an observable fact (Broese van Groenou et al., 2012:275).

Loneliness is the result of the absence of close relationships (Kitzmüller, Clancy, Vaismoradi, Wegener & Bondas, 2018:213), and it is something that is experienced by many elderly people. According to Crewdson (2016:1) loneliness can be defined as "a complex set of feelings encompassing reactions to the absence of intimate and social needs", which is often a result of social isolation. Crewdson (2016:1) distinguishes between two types of loneliness, namely social loneliness and emotional loneliness. Social loneliness is seen as an absence of belonging to a community or group of friends, while emotional loneliness is considered as an absence of deeper connections to attachment figures, such as a spouse or a close friend (Crewdson, 2016:1; Kitzmüller et al., 2018:213). Santrock (2015:585) states that loneliness and social isolation among the elderly have been linked to an increase in health problems and

morality, as well as to a decline in cognitive functioning. The view of Kitzmüller et al. (2018:214) concurs with the above in stating that loneliness signifies a noteworthy health problem and is linked to a greater mortality risk for lonely older adults. Data collected and analysed by Kitzmüller et al. (2018:218) reveals that loneliness is often perceived as a wall that separates older adults from their surroundings, “leaving them disconnected, helpless, and confined to an empty and boring life”; and because loneliness is not perceived to be an optional state, there is often little chance to escape this fate.

Furthermore, Brimelow and Wollin (2017:2) assert that research has established that there is a significantly increased risk of AD diagnosis and dementia onset associated with loneliness, and these are often key factors which may lead to admission in long-term care facilities (LTCFs). Although loneliness has been proven to be a cause of reduced quality of life among the elderly, it is severely underestimated, and the fact that it can affect wholesome behaviour, physical and mental health in several ways continues to be ignored (Crewdson, 2016:7). Bishop (2014:9) asserts that although the vision of living to be 80, 90, or 100 years old is a certainty for millions of people there seems to be two crucial elements to achieving this: quality social connections and contemplation. Being surrounded by noble people such as family members, community members, senior care service providers and practitioners, who honestly and empathetically care about the emotional security and wellbeing of the elderly, is beneficial to the overall wellbeing of an older person (Bishop, 2014:9). Good social relationships and support, along with a dynamic way of life, positive coping skills and the absence of disease are key aspects of successful aging (Santrock, 2015:591).

As the world’s aging population continues to grow, the number of older persons in need of care will increase as well. AD has a severe impact on the physical, cognitive and social aspects of the diagnosed individual. AD is a medical disease for which there is presently no cure, and much of the relational strain that follows an AD diagnosis occurs because the individual with the disease loses the capacity to manage his or her side of the relationship, driving the emotional connection into rough and unfamiliar waters (Barr et al., 2016:41, 44). AD is a degenerative disease that does not merely touch one person, but the whole family and friend circle of the person living with Alzheimer’s are

impacted (Woolsey, 2013:197). The elderly is often pushed aside and isolated, and this is even more of a reality for those living with AD.

2.5 THE PARENT-CHILD RELATIONSHIP THROUGHOUT THE LIFE CYCLE

Amid the numerous facets of well-being in later life, the relationship and bonds with adult children have consistently been acknowledged as having significant effects on older adults' well-being (Chai & Jun, 2017:355). The relationship between children and parents unavoidably changes as both grow older (Kunz, 2013:176), yet the parent-child relationship remains one of the most significant and fundamental relationships in the life of both members of the dyad. Studies show that the parent-child relationship continues to maintain a place of immense importance throughout the life course (Brzozowski, 2013:2).

As older adults maintain ties with their adult children, they seem to cope better with negative events such as the death of a loved one, illness or functional deterioration, and they are able to preserve a mentally and physically healthier condition (Chai & Jun, 2017:355). Adult children and their parents are connected through many forms of intergenerational cohesion and even if parents and their adult children no longer reside in the one household, they assist each other by providing financial sustenance, care, and other forms of assistance (Isengard & Szydlik, 2012:450). As they continue to age, older adults depend heavily on the support and care provided by their adult children, showing that relationships with children play a particularly important role in later life (Chai & Jun, 2017:358). A number of studies, according to Chai and Jun (2017:358), have shown that older adults who do not have strong relationships with their children have poorer levels of life satisfaction; whereas those who have regular interaction and exchanges of support with their adult children show greater levels of life satisfaction and happiness (Chai & Jun, 2017:358). Like sibling relationships, parent-child relationships are uncertain, and even after emerging adults have left the nest, there are likely to be strains in most parent-adult child relationships (Sigelman & Rider, 2015:489). Family conflict and tensions which stem from years, or even decades, do not automatically disappear, and to maintain the desired contact and a relationship, some parents and their children avoid or ignore the issues that cause stress and conflict (Kunz, 2013:176). Schwartz and Scott (2010: 412) assert that regardless of

past tensions or conflict, most adult children and their older parents like one another, enjoy spending time together and are satisfied with their relationships.

Parents and children are at different points in the life cycle, and as a result parents tend to be more invested in the parent-child relationship than the children, whose focus is on building their own families (Sigelman & Rider, 2015:489). However, as the world's population continues to age, more and more older persons start to rely on the support of and assistance by others, and adult children frequently provide such support with daily activities (Heid, Zarit & Van Haitsma, 2016:46). Spouses are the first line of defence when sickness strikes, followed by adult children; however, compared with spouses, adult children provide care over a longer period (Schwartz & Scott, 2010:418).

Most often, ageing families do not experience a role reversal in which the parent becomes the child and the child becomes the caregiver. However, only when the parents reach an advanced age and develop serious physical or mental problems does the parent-child relationship sometimes become affected (Sigelman & Rider, 2015:490). It is a common occurrence for family members to step in and provide necessary support to aging individuals for a variety of needs, and in these instances, families are called to find a balance between their needs and their older relatives in care (Heid et al., 2016:46). As the number of persons diagnosed with dementia and specifically AD increases, there is likely to be an increase in the number of adult children who are faced with either caring for their demented parent themselves or making the decision to place them in a care institution.

2.5.1 Dementia, the older parent and the adult child as caregiver

Caring for someone with degenerative dementias, such as AD, can be a frustrating, traumatic and stressful process, which can continue for many years (Howe, 2015:248; Souter, 2015:172). Being a caregiver for a spouse or an elderly parent who has developed dementia is often a demanding and psychologically agonising experience (Howe, 2015:248; Passer et al., 2009:561). The tremendous burden of caring for someone with Alzheimer's at home becomes physically and emotionally overwhelming (Sarafino & Smith, 2012:316). Caregivers may become so focused on meeting their

loved one's needs that they neglect their own (Howe, 2015:89; Schwartz & Scott, 2010:420). These caregivers often face tremendous burnout as they are unaware of the resources available to them.

Most of those who provide care for a family member are also juggling a career and a family of their own. Individuals living with AD begin to rely more upon the provision and compassion of their care partners as the disease progresses. An unequal dyad usually exists when someone is caring for a dependent person, and as a result the relationship between the two becomes one in which "one person mainly gives and the other mainly receives" (Barr et al., 2016:78, 80 & 90). A research report compiled and published by Alzheimer's Research UK (2015:35) confirmed that caring for someone with dementia places a massive amount of pressure on the carer's physical and mental health, and often it strains, sometimes to breaking point, the relationships with other family members.

Dementia is a lengthy and multifaceted disease which places huge strain on family systems. Dementia affects both the diagnosed individuals and the people closest to them. In comparison to the other chronic illnesses, the slow degeneration, severe dementia related behaviour problems, and the knowing that it will only end when the patient passes away, largely makes dementia a more difficult disease for families to deal with (Sarafino & Smith, 2012:317). Every person who knows the individual with AD must struggle with the fact that he or she is no longer the same "spouse, parent, sibling or friend" they knew prior to the disease setting in. Whilst there is relief in the knowledge that the person has not deliberately changed, this understanding does not make day-to-day life easier for family care providers (Barr et al., 2016:76). The contribution and involvement of relatives and friends is instrumental to the quality of life of people living with dementia (University of Western Sydney, 2011:2), yet Barr et al. (2016:47) assert that one of the aspects that complicates the parent-child relationship is the fact that the adult child is often consumed by the fear that "they are going to get it too", and as a result the adult child naturally withdraws from their parent living with AD, because the busier they are with life and the less time they have to face the realities of the disease, the less they have to confront the possibility that they too might get the disease. Sometimes this withdrawal and avoidance is intentional, but often it happens without the adult child really being aware that they are behaving in

this manner. The reality is that if they are so uncomfortable with the notion of dementia in themselves or their parent that they do not know what to say or how to act, they will back away to escape the reality of the disease (Barr et al., 2016:47). AD generally disconnects the emotional connection amongst family members (Barr et al., 2016:48), and this is often especially true for the parent-child relationship.

Many families have little understanding of the natural course of dementia (Peixoto, Da Silveira, Zimmermann & Gomes, 2018:84); and there are numerous people who are not aware that AD is in fact a terminal illness (Stirling, Andrews, McInerney, Toye, Ashby & Robinson, 2011:5). Because the person with AD declines so gradually their death is usually not linked to the disease; however, recent studies have confirmed that dementia does in fact cause and lead to the death of those living with the disease (Stirling et al., 2011:5). Although dementia is a terminal illness, not enough is known about the disease to tell people living with dementia, or their families, what the life expectancy is for someone with the disease (Stirling et al., 2011:7). The death of a parent is a normative life transition that most will experience (Sigelman & Rider, 2015:557), but for the adult child who has a parent living with AD, their parent “dies” daily as the disease slowly destroys the parent they knew.

2.6 THE SYSTEM’S PERSPECTIVE: ALZHEIMER’S DISEASE AND THE FAMILY

During the 1980s and 1990s, people living with dementia were mainly seen as “empty shells”, “passive victims”, “sufferers”, and as those who experienced a “loss of self”. This was because the predominant approach was biomedical, which meant that individuals diagnosed with dementia were having “little agency, control, awareness, or insight” (Morhardt & Spira, 2013:38). Luckily research done on dementia has managed to shed new light on the reality of the disease and determined that moving away from the medical model of deterioration and misery, universal multidisciplinary approaches to dementia propose that well-being can in fact be sustained despite the onset of progressive cognitive impairment (McGovern, 2010:179).

Personhood is defined as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust” (Palmer, 2013:224). Recognising personhood includes identifying

the “needs, wants, emotions, personality, relationships (or need for relationships) and life story of the individual”, and peoples’ perception of the personhood of someone with weakened cognitive capacities may change with a diagnosis of dementia (Palmer, 2013:224). Palmer (2013:224) continues to state that when a person with diminished cognitive capabilities is seen as someone who is no longer a perceiving and responding individual, their concerns, moods, behaviours, and backgrounds are often overlooked or disregarded. Protecting and promoting the personhood of someone living with dementia is essential, and Barr et al. (2016:42) state that even though AD is a progressive and terminal disease, and although people living with dementia have great difficulty in connecting their thoughts, they are still human beings who can feel deeply.

The world’s population is currently aging at an unparalleled speed, and as a result there is an increase in the number of older adults who are relying on family members, especially on their adult children, to care for them (Murphy et al., 2015:238; Raggi, Tasca, Panerai, Neri & Ferri, 2015:77). The role that the family plays in the health of its members is crucial from birth to death, and although the family system itself and the world in which it operates is ever changing, its role in the health of its members remains vital (Antonucci & Wong, 2010:512). The family is one of our most valuable and cost-effective resources, and its part in protecting the older persons in our society must be reinforced and amplified (Antonucci & Wong, 2010:527). Although the family plays a vital role in ensuring the health of older family members (Antonucci & Wong, 2010:527), it is essential to note that the family cannot do it by themselves, and they can only be the first line of defence if they themselves are supported and edified on AD, what it does and where they can find the support they need.

The extension of later life has intensified the pressure on sons and daughters who must cope with “divided loyalties and a complex juggling act between caregiving for aging parents and grandparents, childrearing, and providing financially for the family” (Rolland, 2016:452). Whilst more and more adult children are starting to care for their aging and frail parents, and continue to tend to their own children, spouses and careers, it is important to note that taking on the role of caregiver can significantly affect the entire family system (Murphy et al., 2015:248). An approach constructed on the family systems perspective and performance theory that places dementia in an

“personified social context of relatedness, allows for new outcomes to emerge, and understanding dementia as an interpersonal dynamic rather than a subjective experience defies common beliefs about the illness” (McGovern, 2010:179).

Viewing the social network, particularly the family, and the dementia experience from a systemic perspective it is easy to recognise that dementia has an impact on the entire family (Morhardt & Spira, 2013:37). AD threatens the functioning and the stability of the entire family system, with all its subsystems, and therefore the interplay between the demented parent and the adult child need to be handled with care. For instance, to preserve the dignity, respect and meaningful involvement of the older parent in decisions pertaining to their own care, the adult child may need assistance in ensuring that they make appropriate shifts to address any discomfort or conflict that might arise as a result of the dynamic between dependency and caregiving (McGoldrick & Sibusawa, 2016:393). “As relational-focused, or family-centred care, relies on the recognition of the interaction of the participants, those with dementia, and those without”, the dynamic and relational view of the individual’s life needs to be taken into consideration to really comprehend the entire experience of dementia (Morhardt & Spira, 2013:37). An AD diagnosis is a personal experience that impacts everyone differently.

The progressive cognitive decline, which is an inevitable consequence of AD, eventually results in the widespread need for care within several years after clinical diagnosis (Hampel et al., 2011:719). AD can occur in middle age, but with old age a diagnosis of AD becomes more likely. Unless means of preventing or slowing down this progressive disease is found, more and more people will end up living with AD, as an increasing number of people are living longer and growing older (Sigelman & Rider, 2015:531). The global cost associated with caring for individuals living with dementia is projected to escalate as the world’s population continues to age, and this must prove to be red flags for existing and future care facilities (Howe, 2015:248).

For older family members who are used to and who value managing themselves and being independent, aspects such as deteriorating health, financial stability and dependency are particularly difficult to accept (McGoldrick & Sibusawa, 2016:393). The incapability to shift relational status can transpire when older adults have trouble

accepting their dwindling powers, or when they perceive that the younger members of the family treats them discourteously or as being useless (McGoldrick & Sibusawa, 2016:393). When older parents become quite frail, or begin to lose their mental or physical capacities, it should not be a time for “intergenerational role reversal”, and adult children should caution themselves in labelling their parents as being “child-like”. In the generational hierarchy, parents always remain parents to their children (McGoldrick & Sibusawa, 2016:393) regardless of their mental or physical ability. McGovern (2015:411) asserts that people living with AD have identified the “loss of self and the loss of a shared sense of relatedness” as two of the most difficult aspects of the disease. Despite the various debilitating aspects of AD, McGovern (2015:416) is of the opinion that the “intimate care dynamics” of AD can be sustained granted that those involved make the relevant and necessary adjustments.

2.7 SUMMARY

In this chapter the researcher discussed various aspects of the family systems approach; she looked at the how the parent-child dynamic changes throughout the life cycle; and she further elaborated on why this approach assisted in understanding that AD does not merely impact the diagnosed individual but has a ripple effect throughout the entire family systems and other systems in which the diagnosed individual functions.

The correlation between global population ageing and the rise in the number of people living with dementia worldwide was reiterated. Additionally, the impact that global ageing has not only on the economy, but also on health services and the family system was further emphasised. An AD diagnoses does not merely impact and disrupt the life of the diagnosed older parent, and in this chapter the researcher attempted to shed light on the ripple effect that an AD diagnosis creates in the family system. The number of people living with dementia globally is on the rise, and this poses a challenge for the world’s public health sector. The lack of support services, policies and care facilities available to those living with dementia and their families in Namibia, was mentioned and this will be discussed in more detail in the next chapter.

CHAPTER 3

ALZHEIMER'S DISEASE CARE MANAGEMENT IN THE NAMIBIAN CONTEXT

3.1 INTRODUCTION

One of the primary causes of death and disability globally are chronic diseases, and as the global population continues to age the prevalence of chronic conditions will increase (Cramm & Nieboer, 2012:279). These chronic diseases often coincide and the “morbidity, mortality, health-care resource utilization and costs” that accompany these conditions impose an enormous burden on patients, medical professionals and societies (Cramm & Nieboer, 2012:279). One of these chronic conditions and most consuming mental health disorders diagnosed in older persons is dementia, a progressive brain disease of which AD is the most common cause (Alzheimer's Association, 2017:326; Alzheimer's Society, 2014a:1; Fazio, Pace, Maslow, Zimmerman & Kallmyer, 2018:1; National Institute on Aging, 2015:3). The impact of this neurological disease on the individual and their families is extensive (Barr, Shaw & Chapman, 2016:35; Houghton, Murphy, Brooker & Casey, 2016:105;).

The risk of developing dementia rises significantly with age. Global ageing means that people are living longer than ever before and, although AD is not a normal part of ageing, with old age the risk of developing dementia is significantly greater (Cahill, O'Shea & Pierce, 2012:28). Dementia is a major public health problem worldwide, and unless a cure is found dementia is set “to become a worldwide epidemic” (Cahill et al., 2012:28; Houghton et al., 2016:5; Thoma-Lürken, Bleijlevens, Lexis, de Witte & Hamers, 2018:29), and Namibia will be no exception to this phenomenon. Since no cure is anticipated soon, many people will die with or from dementia (Van der Steen, Radbruch, Hertogh, de Boer, Hughes, Larkin, Francke, Jünger, Gove, Firth, Koopmans & Volicer, 2014:198). Globally the cost of dementia is rising, both financially and in terms of burden of disease, and in many countries, dementia has become a chief health policy priority (Houghton et al., 2016:105; WHO, 2017b:2). The WHO considers dementia as a high priority public health issue and emphasises the importance of better care and more support to caregivers (Albers, Van den Block & Vander Stichele, 2014:107). Dementia has not received much attention in the past and more needs to

be done to ensure that health systems are equipped to deal with the ever-increasing number of dementia cases.

3.2 ALZHEIMER'S DISEASE: THE MOST COMMON TYPE OF DEMENTIA

Just like coronary artery disease is a type of heart disease, AD is a type of brain disease (Alzheimer's Association, 2019:5). AD is the most common type of dementia, and it is an incurable, degenerative disease in which atypical proteins collect in the brain cells (Alzheimer's Society of Canada, 2016a:1; Alzheimer's Association, 2019:5). As these protein clusters continue to collect, AD slowly damages or destroys the neurons in the brain which are involved in all cognitive functions such as thinking, learning and memory (Alzheimer's Association, 2019:5). Usually, persons live with Alzheimer's symptoms for years, and over time, these symptoms have a tendency to increase and begin to interfere with the individual's ability to complete everyday activities (Alzheimer's Association, 2019:5). It is at this stage where the individual is said to have "dementia due to Alzheimer's disease" or "Alzheimer's dementia" (Alzheimer's Association, 2019:5).

AD is a fatal disease as there is currently no cure. As the disease progresses and neurons in other parts of the brain are damaged or destroyed, the activities that was a core part of the individual's identity, such as working or planning family events, may no longer be possible (Alzheimer's Association, 2019:5). Ultimately, neurons in the parts of the brain that allow a person to carry out basic bodily functions, such as walking and swallowing, are affected (Alzheimer's Association, 2019:5). As the disease continues to progress and more neurons in different parts of the brain are damaged or destroyed, the person with AD becomes less independent and increasingly more dependent on continuing care from others.

3.2.1 Signs and symptoms of Alzheimer's disease

AD causes symptoms of dementia such as "memory loss, difficulty performing daily activities, and changes in judgement, reasoning, behaviour and emotions" (Alzheimer's Society of Canada, 2016a:1). These dementia symptoms are irreversible, and as such any loss of abilities cannot come back (Alzheimer's Society of Canada, 2016a:1). The

earliest symptoms of AD vary from one individual to the next, but memory difficulties are usually one of the initial signs of cognitive impairment related to AD (National Institute on Aging, 2017). Deterioration in the non-memory facets of cognition, such as “word-finding, vision/spatial issues, and impaired reasoning or judgment”, may also signal the very early stages of AD (National Institute on Aging, 2017). The onset, signs and symptoms of AD vary from person to person, and as the individual with AD progresses through the three primary stages of AD, their symptoms usually become more severe.

3.2.2 Stages of Alzheimer’s disease

Changes in the brain related to AD commence many years prior to any signs of the disease, and this time period, which can last for years, is referred to as “preclinical Alzheimer’s disease” (Alzheimer’s Association, 2018c:1). The average life expectancy for persons with AD vary. However, on average, an individual with AD lives four to eight years after being diagnosed, but they can live as long as 20 years depending on age and other health conditions (Alzheimer’s Association, 2018c:1). Typically, AD progresses slowly through three general stages which bring about significant changes in the person’s and family’s lives: early (mild), middle (moderate) and late (severe) (Alzheimer’s Association, 2018c:1; Alzheimer’s Society of Canada, 2019). AD affects all people differently and in diverse ways, and as such the timing and severity of dementia symptoms differs as each person progresses through these stages differently (Alzheimer’s Association, 2018c:1). It is important to note that the stages of AD are able to overlap, and as a result it may prove difficult to place a person with AD in a specific stage (Alzheimer’s Association, 2018c:1; Alzheimer’s Society of Canada, 2019).

3.2.2.1 Early stage Alzheimer’s disease (mild)

Early stage refers to persons of any age who have suffered mild impairment due to AD (Alzheimer’s Society of Canada, 2019), and whilst in this stage the person living with AD often retain their physical capabilities and are able to live independently (Alzheimer’s Society of Canada, 2019; Alzheimer’s Association, 2018c:1). Regardless of this, the person with AD may feel as if they are beginning to have memory lapses,

such as forgetting familiar words or the location of everyday objects (Alzheimer's Association, 2018c:1). The recognition that something is wrong often gradually becomes apparent to the person and his or her family (National Institute on Aging, 2017). In mild AD, individuals may appear to be healthy, but they soon experience more and more difficulty making sense of the world around them (National Institute on Aging, 2017). In this stage of AD, most people are able to function independently in many areas, but it is likely that they will need help with some activities to make the most of their independence and remain safe (Alzheimer's Association, 2019:6). It is possible for people with dementia to take control of their health and wellness while in the early stage, by concentrating their energy on the parts of their life that are most meaningful to them (Alzheimer's Association, 2018c:1). Additionally, this is the perfect time to put legal, financial and end-of-life plans in place as the person with dementia is still able to be part of the decision making process (Alzheimer's Association, 2018c:1). Receiving an AD diagnosis is never easy, and in this stage the diagnosed person needs the support and understanding of family members and friends.

3.2.2.2 Middle stage Alzheimer's disease (moderate)

In the moderate stage of AD, which is often the longest stage and can last for many years, individuals will require a greater level of care (Alzheimer's Association, 2018c:2; Alzheimer's Association, 2019:6). This stage brings greater deterioration in the person's cognitive and functional skills, and memory and other cognitive abilities will continue to deteriorate (Alzheimer's Society of Canada, 2019). The individual may confuse words; get frustrated, angry, agitated or anxious more easily; act in unexpected ways; have difficulties communicating and performing routine tasks such as taking a bath and getting dressed; unable to learn new things; experience difficulty recognizing family members and friends; become incontinent at times; and start having personality and behavioural changes (Alzheimer's Association, 2018c:2; Alzheimer's Association, 2019:6; National Institute on Aging, 2017). Although individuals in the middle stage of AD experience a tremendous number of setbacks and losses, they are still able to participate in daily activities with assistance, and it is vital to establish what the person can still do or find ways to simplify tasks (Alzheimer's Association, 2018c:2). In this stage, the need for more intensive care increases (Alzheimer's Association,

2018c:2), and family members may need to make the very difficult decision to place their loved one in a care facility that can provide for their extensive needs

3.2.2.3 Late stage Alzheimer's disease (severe)

In the late stage of AD, individuals are completely dependent on others to meet even their most basic needs, and they require around-the-clock care (Alzheimer's Association, 2018c:2; Alzheimer's Association, 2019:6; National Institute on Aging, 2017). In the final stage of the disease, individuals often completely lose the ability to communicate with or recognise loved ones, they experience difficulty swallowing, lose control over their bladder and bowel movements, and eventually they lose complete control of their movement (National Institute on Aging, 2017; Alzheimer's Association, 2018c:2). In this stage, the person may be in bed most or all of the time as the body continues to shut down (National Institute on Aging, 2017). AD is fatal, and loved ones often experience the devastation of this disease first hand. The person living with AD and their family members need support throughout the different stages of AD.

3.3 DEMENTIA CARE

Dementia is poorly diagnosed worldwide, and, if a diagnosis is made, it is usually at a late stage in the progression of the disease (WHO, 2017b:2). Presently, a huge gap exists between the need for prevention, treatment and care for dementia and the actual provision of these services. Long-term care which stems from diagnosis until the end of life for people with dementia are often disjointed if not completely absent (WHO, 2017b:2). Dementia is a non-communicable disease, and the course of the disease differs for dementia and other patients. For example, cancer patients could possibly experience a significant deterioration in function in the last months or weeks of life, and diseased trajectories are well-defined, whereas, with dementia even though losses are progressive, there may be persistent 'dwindling' and severe disability throughout the course of the disease (Van der Steen et al., 2014:198). The disease trajectory for people with dementia has been described as "prolonged gradual decline" and, compared to cancer dementia can be quite unpredictable (Albers et al., 2014:107). In most cases individual patients will live through the final phase of dementia with severe physical and cognitive impairment; additionally, they may die earlier from "dementia-

related health problems such as pneumonia and intake problems or comorbid disease” (Van der Steen et al., 2014:198). AD is a consuming disease and the individuals living with the disease face many losses throughout their journey with dementia.

With dementia being a progressive disease coupled with cognitive and functional decline, those diagnosed with the disease are increasingly dependent on support and particularly prone to nursing home admission (Hampel et al., 2011:719; Thoma-Lürken et al., 2018:29). Many people with dementia will spend their last years of life in nursing homes or other care facilities and providing them with high quality end-of-life care is extremely challenging and every so often places high emotional and physical stresses on caregivers (Albers et al., 2014:107; Thoma-Lürken et al., 2018:29;). Apart from the progressive cognitive and physical decline faced by most people living with dementia, a research study found that in residential aged care facilities the environment often has a much greater effect on people with dementia than on other older persons due to their reduced ability to adapt (Digby & Bloomer, 2014:35).

Although older adults remain healthy and happy well into their 70’s, advanced age is often accompanied by chronic illness and disability, which pose stressful family caregiving challenges (Walsh, 2016:18). Dementia is a long-term chronic disease, but many people diagnosed with dementia are still otherwise physically healthy (Dementia Action Alliance, 2016:6). However, many individuals living with dementia face severe cognitive and physical decline and often require additional medical attention and care. Hospitalisation may be a terrifying, confusing and terrible experience for people with dementia. Acute hospitalisation is often traumatising for the dementia patient as the person is admitted into an unfamiliar environment and surrounded with unfamiliar faces, hospitalisation can involve several bed-moves between specialty areas, and this increases the person’s disorientation and has a negative impact on their ability to cope (Digby & Bloomer, 2014:35).

One of the most common symptoms of dementia is spatial disorientation, and when a person with dementia is hospitalised, symptoms and behavioural issues accompanying dementia can be aggravated due to the unfamiliar environment (Digby & Bloomer, 2014:35). These symptoms and behavioural issues may include nervousness, violence, withdrawal, navigation difficulties and wandering and for people with

restricted movement outside of their rooms, anxiety can develop as a result of their poor understanding of the unfamiliar ward environment (Digby & Bloomer, 2014:35; Melander, Sävenstedt, Wälivaara & Olsson, 2018:1). Since the challenges of dementia care in acute hospitals are multifaceted it is essential to study the processes through which the care experience of patients with dementia may be impacted by both the physical and social surroundings in dynamic interaction (Hung, Phinney, Chaudhury, Rodney, Tabamo & Bohl, 2017:2).

Furthermore, it is essential that health-care professionals are taught specific expertise to ensure that they can manage the behavioural problems, and are able to anticipate, assess and manage the physical and cognitive problems often displayed by their demented patients (Van der Steen et al., 2014:198). Unfortunately, the traditional medical model and the existing organization of health care delivery are not equipped to wholly address the specific care needs nor support the wellbeing of people living with dementia and their family members (Dementia Action Alliance, 2016:11) The Dementia Action Alliance (2016:11) is of the opinion that although the work of healthcare professionals are highly appreciated and that traditional medicine should be praised for its significant and life-altering advances in prevention, cure and management of many illnesses, the current medical models often fail people and families affected by dementia.

3.3.1 Dementia, dignity and person-centeredness

Protecting the dignity and self-worth of people with progressive dementia is an essential facet of their care from the “perspective of their experience of self and identity and in their participation in daily activities of living” (Melander et al., 2018:1). Dementia patients are deemed to be a vulnerable patient group and dignity should be one of the primary concepts in their care; it can in fact be regarded as a “moral touchstone” (Heggestad, Nortvedt & Slettebø, 2015:825). Heggestad et al. (2015:832) assert that if the dignity of individuals living with dementia is to be protected, the health care they receive needs to be “confirming, person-centred and relational”. For individuals with dementia, dignity-promoting care is care that confirms the person’s personhood and considers them to be relational human beings; medical professionals and other care workers need to respect the individual and relate to them as equals (Heggestad et al.,

2015:835). To ensure that the person is treated with dignity and not as an object of care it is important to confirm the 'whole self'. Confirming care means "seeing and understanding the whole person, meeting the patient on his/her own terms, and seeing the patient as the one he or she really is" (Heggestad et al., 2015:835). Person-centred care ensures that the dignity of those living with dementia is protected and seen as unique individuals.

3.3.2 Person-centred care

Person-centred care focuses on seeing the person behind the diagnosis of dementia and treating that person as a unique individual (Dementia Action Alliance, 2016:14; Heggestad et al., 2015:825). Person-centred care must be a guiding principle and the unique worth of the person needs to be acknowledged in every individual, regardless of cognitive impairment; ultimately, care needs to be provided in such a way that "the person with dementia is valued, respected, treated with dignity and supported to live well with dementia and enjoy a good quality of life" (Cahill et al., 2012:19, 20). Tom Kitwood, a geriatric psychologist, is internationally recognised as the father of person-centred care. Kitwood's theory rejected the traditional medical approach to dementia and instead argued for a more holistic life-world approach to care (Dementia Action Alliance, 2016:15; Edvardsson, Petersson, Sjogren, Lindkvist & Sandman, 2014:270). This person-centred approach to care builds on the biographical information of the individual and family participation to allow collective decision-making, embraces individual experiences of illness and everyday life, and attempts to encourage a continuance of self and "normality in spite of illness, institutionalisation or dependence on care" (De Medeiros & Doyle, 2013:83-84; Edvardsson et al., 2014:270). De Medeiros and Doyle (2013:83) assert that person-centred care has been found to not only improve and ensure the quality of medical and mental health services, but also the formal and informal care for people living with dementia. Person-centred care means that medical professionals, care workers, family and friends look beyond the disease and recognise the entire person.

The person-centred approach embraces a holistic approach to care and looks at what is most important to the individual, including their goals and preferences, and seeks to promote overall wellbeing (Dementia Action Alliance, 2016:14). It is important that all

care and interventions are designed to bring out the best in the person living with dementia, their retained abilities need to be maximised and their journey through dementia should be facilitated through access to quality social and health care services (Dementia Action Alliance, 2016:14). The Dementia Action Alliance (2016:15) further states that:

Person-centred dementia care and support is based on the fundamental belief that every person has a unique background, skills, interests and the right to determine how to live his or her own life. Person-centred dementia support is focused on nurturing the person's emotional, social, physical, and spiritual well-being. This is achieved through reciprocal, respectful relationships by: valuing personal autonomy, choice, comfort and dignity; focusing on the individual's strengths and abilities; enabling opportunities for continuation of normalcy and growth of self; & enhancing individual purpose, meaning, enjoyment and belonging.

If the individual with dementia is to receive and have access to high quality support and health care, a true partnership in care needs to evolve and the interests of professionals and carer workers need to be carefully considered and supported; partnerships between the different role players in dementia care will ensure that the individual is placed at centre stage with "due regard being given to his or her mental and physical well-being, personality, sense of self, cultural and occupational background, relationships and religious/spiritual needs" (Cahill et al., 2012:20). The well-being and autonomy of the person with dementia needs to be promoted while balancing their interests with those of the family caregiver; it is essential that the individual with dementia is seen and treated as a person who has rights and responsibilities who is still able to contribute to society (Cahill et al., 2012:20). A person-centred care approach will protect not only the rights and dignity of the individual with dementia, but it will ensure that the wellbeing of those entrusted to care for the individual with dementia is equally promoted and protected.

Another approach that complements the person-centred approach to care is the Family Systems Approach. The Family Systems Approach aims to involve family members in the care of the individual with dementia. When family members form part of the caregiving team and contribute according to their abilities and resources the burden is removed from the designated primary caregiver (Walsh, 2016:18). As the disease progresses people with dementia become increasingly dependent on their family

members to provide for their daily care and maintain their dignity (Wang, Xiao, He & De Bellis, 2014:1370). The family plays a central role in the care of the individual living with dementia and support from family members is essential in the dementia journey. As the health care status of the elderly parent with dementia declines and the need for care and assistance increases, family caregivers play an instrumental central role in the support of their functional independence and the protection of their quality of life (Hainstock, Cloutier & Penning, 2017:32). However, although the family plays a vital role in the care of their family member living with dementia, taking care of an elderly parent with a chronic illness in their home environment is a heavy burden on all persons involved.

Once the caregiving situation becomes untenable at home, which is often the case, the majority of families turn to the health care system simply because their elderly parent with dementia is progressively declining and the family caregiving demands becomes an increasing burden and the caregiving demands simply become too great to handle alone (DeForge, Ward-Griffin, St-Amant, Hall, McWilliam, Forbes, Kloseck & Oudshoorn, 2017:23; Van der Steen et al., 2014:198). This support often entails caregivers entering relationships with formal care providers who provide care within the home and to people living with dementia. As the demands of dementia care outstrip familial resources, formal (i.e., paid rather than unpaid) carers become involved, often including nurses, therapists, and social workers, as well as para-professional caregivers such as nurses' aides and personal support workers (DeForge et al., 2017:23). In general, it is not often that family caregivers are seen as essential members of the care team when it comes to the long-term care of someone living with dementia; consequently, not a lot of attention has been paid to how these family caregivers aid in the smooth transition of their family member from home care to a nursing home or other care facility despite the fact that this the most common care trajectories experienced by clients (DeForge et al., 2017:23). These transitions are often traumatic for the family member with dementia as well as family members, and it is one of the "losses" that is an unfortunate part of the devastating nature of dementia.

Family members of dementia patients are too often "the silent sufferers in the tedious and often prolonged process of caregiving" (Pattanayak, Jena, Tripathi & Khandelwal, 2010:112). Cahill et al. (2012:20) state that adopting multiple perspectives to dementia

care, such as the person-centred and family systems approach, will aid in the support of family caregivers. It will furthermore mean the individual with dementia is supported from the day they receive their diagnosis to the time of their death, irrespective of the availability and usefulness of treatments; advising the PWD on lifestyle risk factors which may hasten or exacerbate the dementia; providing individualised, responsive and flexible social and personal care services which are strengthened by ethics that respect the PWD's rights and autonomy; and listening to the wishes, preferences and needs of PWD.

To effectively address the magnitude and often complex needs of persons living with chronic-illness, approaches that “include collaboration among health-care professionals from various organizations, and extend beyond traditional acute episodic health care and the services of any single organization” is required; and as such alternative models of health-care and partnerships between different organisations and professionals needs to be explored (Cramm & Nieboer, 2012:279).

To assess whether the Namibian health care system is equipped to deal with the complex and special needs of people living with dementia and their family members, the researcher explored the various facets of health care in Namibia and assessed whether the dignity of persons with dementia is protected and considered in the health-care system.

3.4 THE NAMIBIAN HEALTH CARE SYSTEM

Namibia is a vast country, situated in south-western Africa, that covers approximately 824 292 square kilometres (Government of Namibia, 2018; Ministry of Health and Social Services & Namibia Statistics Agency, 2014:1). In 1991, the Namibian government conducted the first population and housing census since independence, with the names of 1 409 920 Namibians recorded (National Planning Commission, 1994:7). The Namibian population census is conducted every ten years (Ministry of Health and Social Services & Namibia Statistics Agency, 2014:2), and the next census is set to take place in 2021. According to the most recent data documented in the 2011 Population and Housing Census, the country's population stands at 2,113,077, which indicates growth of 1.5 percent in the last 10 years (Ministry of Health and Social

Services & Namibia Statistics Agency, 2014:2); however, it is estimated that the Namibian population currently amounts to 2.59 million (two million five hundred and ninety thousand) (World Population Review, 2018). Although Namibia is not nearly as densely populated as many other countries, the unremitting addition of new citizens to its population requires that the sphere of service delivery be broadened.

The quality of a health care system and services in the society is seen as one of the central elements that define a government; and although the health care system and services vary from one country to another, given the health care policies of that certain state, quality health care services are central to the wellbeing of every nation (Furnell, 2017). In 1900, the universal average life expectancy was a mere 31 years, and well below 50 in even the wealthiest of countries. However, with advances in the health care system and services (Furnell, 2017), most states now have a life expectancy of around 70 years, with developed countries having significant populations over 80 years old (Vikas, 2014). Today, demographic ageing is a world-wide trend, with populations in low- and middle-income countries ageing the fastest; it is projected that the number of people aged 65 and older will outnumber children for the first time in history by the middle of this century (Chan, 2017:108; Bamford & Serra, 2011:7; Guerchet & Aboderin, 2017:10).

In a recent report by the WHO, the Director General Dr Margaret Chan (2017:2) states:

The challenges facing health in the 21st century are unprecedented in their complexity and universal in their impact. Under the pressures of demographic ageing, rapid urbanization, and the globalized marketing of unhealthy products, chronic non communicable diseases have overtaken infectious diseases as the leading killers worldwide.

Dementia is one of the non-communicable diseases that has become a major public health concern (Albers et al., 2014:107; Fulmer & Nanxing, 2017:162) and it not only impacts the mental health of the global population but has widespread consequences for all sectors of society. Dementia is a one of the primary causes of disability and dependency amid older adults globally (Cramm & Nieboer, 2012:279; Guerchet & Aboderin, 2017:10), and has an impact not only on individuals living with the disease but also on their caregivers, families, communities and societies (WHO, 2017b:2). Dementia has emerged universally as one of the 15 primary causes of 'Disability

Adjusted Life Years (DALYs)' (Guerchet & Aboderin, 2017:13). It is estimated that dementia currently accounts for over 11.9% of the years lived with disability due to a non-communicable disease; and with the enhanced life expectancy worldwide, this figure is anticipated to increase even more (Hung et al., 2017:2; WHO, 2017b:2). Although non-communicable diseases have been acknowledged to be a pressing global health challenge, dementia has been somewhat neglected in universal agreements, plans and policy guidelines; and despite the anticipated growth in AD and other forms of dementia, "dementia is linked more to disability than to mortality and therefore has been historically overlooked as a policy priority" (Bamford & Serra, 2011:8). Dementia leads to increased costs for governments, communities, families, individuals, and the current and future economic development of all countries (Bamford & Serra, 2011:9; Chan, 2017:108) and it cannot be disputed that dementia will not equally have severe cost implications for Namibia in the near foreseeable future. Although not all older adults need assistance with their day to day activities, many do require some sort of support to continue to live independently in their homes and this holds true for older persons who have no health issues, as well as those who are living with dementia and AD (Dementia Care Central, 2016a). The WHO (2017d) states that it is imperative to prepare health providers and societies to meet the needs of older populations, and this includes:

- Training for health professionals in providing care for older people.
- Preventing and managing age-associated chronic diseases including mental-neurological and substance use disorders.
- Designing sustainable policies on long-term and palliative care; and
- Developing age-friendly services and settings.

The natural progression of AD will unfortunately result in the need for care for the person living with the disease, and the level of care and supervision required will depend on the stage of AD and their ability to function (Dementia Care Central, 2016b; Hampel et al., 2011:719; Thoma-Lürken et al., 2018:29). Due to the progressiveness of the disease, dementia care is a specialised field and requires that all those in the medical profession, including those who care for older persons in old age homes, understand the complexity of the disease and receive training on how to properly care for someone living with dementia and AD. Of all mental disorders, dementia is said to

be the most overwhelming, expensive, intensely feared, and poorly understood by both populations and the medical profession (Chan, 2017:111). In this section, the researcher attempted to attest the extent to which dementia is misunderstood, neglected and inadequately prepared for in the Namibian health care system.

3.5 HEALTH AND MENTAL HEALTH

3.5.1 The right to health

Human rights are inherent to all human beings, legally protected and guaranteed by law, and they protect individuals and groups against actions that interfere with their basic freedoms and human rights; all human beings are entitled to these rights without discrimination (Legal Assistance Centre (LAC), [sa]:1; UN, [sa]). The right to health is a fundamental human right that needs to be prioritized. On the 11th of May 2000, the UN adopted General Comment No. 14 (2000) of the Committee on Economic, Social and Cultural Rights (2000:1). The following is included in General Comment No. 14:

Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. The realization of the right to health may be pursued through numerous, complementary approaches, such as the formulation of health policies, or the implementation of health programmes developed by the World Health Organization (WHO), or the adoption of specific legal instruments

The right to health means that the government has the responsibility to put in place conditions in which citizens can be as healthy as possible (LAC, [sa]:3). The right to health is accepted in the United Nations International Convention on Economic, Social and Cultural Rights, Article 12, which states that countries such as Namibia, “who have ratified the Convention must recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and they must take steps to achieve the full realization of this right” (Walters, 2014:6).

The right to health is further recognised in various international instruments to which Namibia is a party, and they are: the Universal Declaration of Human Rights, Article

21(1); International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), Article 5(e)(iv); the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), Articles 11(1) (f), 12 and 14(2) (b); the Convention on the Rights of the Child (CRC), Article 24; and the Convention on the Rights of Persons with Disabilities (CRPD), Article 25 (Walters, 2014:7). Namibia is party to a body of non-binding international standards and declarations relating directly and indirectly to the right to health, i.e. the Declaration of Alma-Ata, the United Nations Millennium Declaration and Millennium Development Goals, and the Declaration of Commitment on HIV/AIDS; however, at regional level the country also subscribes to the African Charter on Human and Peoples' Rights and the African Charter on Rights and Welfare of the Child (Walters, 2014:7).

In 2009, the Namibian Ombudsman, Adv. John R. Walters examined the true extent of the protection and/or violation of human rights in Namibia. One of the key areas identified, which needs dire attention, is the “right to health” of each Namibian citizen (Walters, 2014:3). In his report, the Ombudsman indicated that with regards to the right of health of each Namibian citizen, the vision to be achieved is: “a Namibia where every citizen enjoys access to quality, affordable and accessible health care towards attaining and sustaining highest standards of physical and mental health” (Walters, 2014:7). Rolf Hansen, Chief Executive Officer of the Cancer Association of Namibia said that, although quality and equitable healthcare is a basic human right, it is a luxury which only a few have access to in most parts of the world (NAMPA, 2018). Access to quality health care is said to be recognised as basic human right in Namibia. The unfortunate truth, however, is that to the majority of Namibians quality healthcare is a luxury and not a right. The grim and unfortunate reality remains, 28 years after independence most Namibian citizens do not enjoy access to quality, affordable or accessible health care.

3.5.1.1 The right to mental health

Clear distinctions have been made between the human body and the human mind; however, mental health and physical health cannot be separated or discussed as individual entities (Mental Health Foundation, 2018). Mental health speaks to more than just the absence of mental illness; it is an indispensable part of overall wellbeing,

needs to be a priority and receive as much attention as physical health (Sanicola, 2016; WHO, 2018). Mental health has a profound effect on overall wellbeing, and it has been found that poor mental health has a negative impact on physical health and can lead to an increased risk of developing certain medical conditions (Mental Health Foundation, 2018; Molas, 2016:1265). Essentially, “there is no health without mental health” (WHO, 2018).

Health, which includes mental health and wellbeing, is a complex and all-inclusive concept which includes various aspects (Fawcett, Weber & Wilson, 2012:102). In the constitution of the WHO, health is described as, “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (WHO, 2018). Fawcett, Weber and Wilson (2012:141) similarly assert that mental wellbeing and mental ill-health is viewed as, “dynamic and constructive and as open to a range of understanding and meanings which reflect context, the constantly changing interaction between an individual and their environment and the way in which these are interpreted”. Mental health is crucial to the human race’s shared and individual ability to reason, interrelate with one another, make a living and enjoy life; therefore, the protection, promotion and restoration of mental health should be a chief concern universally (WHO, 2018).

The right to the highest attainable standard of physical and mental health is a fundamental human right crucial for the exercise of other human rights (United Nations Human Rights Council, 2017:3). Yet, persons living with mental health problems experience several forms of discrimination in their society which can impede their ability to lead meaningful lives (Dementia Action Alliance, 2016:9; Molas, 2016:1265;). Molas (2016:1265) further draws from an article published by Harding (2000) in the *Acta Psychiatrica Scandinavica* journal and states that individuals living with a mental health illness suffer more from the social consequences of their disorder than from the real psychopathology because, not only do they have to deal with the symptoms of their illness but “they are subject to coercive and repressive forms of abuse and large scale neglect which comes either from chronic institutionalisation in inhuman and humiliating conditions or through deinstitutionalisation and the failure to provide adequate community care” (Molas, 2016:1265). Gable (2012:232) contends that individuals with mental health issues experience systemic barriers to access, including

poor mental health infrastructure, absence of mental health facilities and well-trained professionals who can administer adequate mental health care, as well as costly treatments which several people can not to afford.

Even though research has proven that poor mental health negatively impacts individuals and their communities, mental health care and the health systems that should be established in order to provide treatment is unfortunately more often than not “low priority, receiving stunted budgets, inadequate resources, and little attention from government” (Molas, 2016:1266). In March 2017, a business delegation from Finland visited Namibia with the aim to explore potential collaboration in the health sector and one of their key findings was that there is dire need to construct more facilities for people with mental health problems (Kapitako, 2017). During their visit, Mrs. Leena Lehtonen, the finance director of Sopimusvuori (LTD), noted that there are limited mental hospitals in the country to care for persons with mental illnesses, and she added there is a need for people with mental illnesses to have “daycare facilities, where they can be rehabilitated once discharged from hospital” (Kapitako, 2017). She further observed that once patients are discharged from the hospital, they have no other option but to return home, and family members who often do not understand their condition or the complex needs associated therewith are tasked to take over the responsibility of primary care givers (Kapitako, 2017).

Apart from the state’s mental health care services there are private psychiatrists and psychologists who provide mental health services in Namibia, but these services are restricted to those individuals who can afford it (Kapitako, 2017). The number of people living with a mental health condition, such as dementia, is increasing as the population continues to grow; and as such the health care system, which includes the workforce and the physical environment of hospitals, needs to adapt and become more responsive to the changing healthcare needs of the population (Hung et al., 2017:2).

Mental health is an inclusive component of overall wellbeing and is included under the right to health of each Namibian; yet, the protection and promotion of mental health and the scope of mental health services in Namibia seems to be on the back burner and is guided and bound by the obsolete Mental Health Act 18 of 1973. In an interview with the New Era newspaper the current Deputy Minister of Health, Juliet Kavtuna

stated that the Ministry has embarked on a process of updating the current Mental Health Act, which she deemed to be obsolete and that it needs to be updated to offer better mental health services to the Namibian population an effort to replace the current obsolete Mental Health Act, the Ministry is in the process of updating the current Mental Health Bill to replace the current Act of 1973, which Health Deputy Minister Juliet Kavetuna says is obsolete (Ikela,2017).

3.5.1.2 Access to quality and affordable health care

Health care is a general term used to refer to a system that comprises the preservation and the development of medical services in order to tailor to the medical demands of the population (Furnell, 2017). As the global population continues to grow, the demands of citizens to quality health services intensifies and cannot be undermined; the importance of health is considered as one of the top priorities of the modern society (Furnell, 2017). Several aspects impact health status and a country's capacity to offer quality health services for its people Ministries of health are important actors in the assurance and deliverance of these health services, but so are other government divisions, donor organizations, civil society groups and communities themselves (WHO, 2008). Namibia has come a far way since independence; service delivery has improved, and technological advancement has allowed for better quality health services. However, quality health services are still not accessible by the entire Namibian population and there is still much to be done before the right to health of each citizen is realised.

3.5.1.3 Quality health care: a right, not a luxury

Namibia runs one of the most expensive health care service delivery models in the world in which government “bears the cost of transporting, lodging and feeding a good number of the 87% of its citizens from the remote hinterland settlements that patronize government health facilities” (Omulabi, 2018/05/09). The cost of medical care is one of the many obstacles that the Namibian population faces in accessing quality health care. It is only the citizens who are “well off” and those who belong to a medical aid fund who can access quality health services in private practice (Omoluabi, 2013:1). Several Namibians spend large sums of money to access health services, and

government needs to do more to ensure that quality healthcare is accessible to everyone (Shapwanale, 2018:5).

During an interview with the Namibian Newspaper, the WHO representative to Namibia, Mr. Charles Sagoe-Moses said that while “9% of the population incur out-of-pocket expenditure, it is not bad for the country when compared to international standards”. However, he stressed that there is a huge problem of accessibility to quality health care services and those who can afford it end up having to spend more to access quality medical care (Shapwanale, 2018:5). Mr. Sagoe-Moses is of the opinion that apart from people getting poor healthcare or them having no access to healthcare at all, Namibians are pushed into poverty simply because they directly and indirectly spend more on accessing quality healthcare than they should. This should not be the case as health is a fundamental human right, and every person must be able to access quality healthcare whenever they need it (Shapwanale, 2018:5).

Omoluabi (2013:1) states that in an assessment conducted by him and his team it was discovered that both major health facilities in Namibia did not conform to “internationally acceptable standards of care in all but one of the service elements, and yet, the general population is left with both these facilities as their main options” (Omoluabi, 2013:1). Although the above was reported on by only one researcher, Namibia’s current Minister of Health Hon. Dr. Bernard Haufiku (2016) said the following about the country’s public health care system during an interview with the New Era newspaper on the 16th of March 2016:

Non-training of specialists in primary health care, non-maintenance of infrastructure, ageing hospitals, shortages of crucial equipment and the procurement of health equipment without prior consultation with operators on the appropriate equipment needed, are but some of the many problems besieging the public health system. In addition, service delivery in the public health sector has not been up to scratch ...

The MOHSS is left powerless by major challenges hindering service delivery to the Namibian public (Smit, 2017). According to the assessment of the MOHSS’s performance in 2016/2017 financial year, many challenges still hamper the delivering of quality health services to the public; the assessment further revealed that there has

been an increased demand for services in both communicable and non-communicable diseases and other social ills (Smit, 2017). A healthy population is an end, besides being one of the most elementary requirements for quality of life, it is also a basic underpinning for a country's economic growth and development (Ministry of Health and Social Services & Namibia Statistics Agency 2014:253). The Minister of Health, Haufiku (2016) stated that as a Ministry, they are planning to transform service delivery in all care facilities, and he was quoted as saying:

We are going all the way not only to train and re-orientate but also to monitor on a day to day basis, literally meaning that we will delegate someone to walk around the hospital to see how service is being delivered, even from just the initial greeting of patients.

Namibia's Founding President, His Excellency Dr. Sam Nujoma, during the celebration of his 89th birthday urged government to invest at least 50% of the country's national budget in education and health saying that "the country is lagging behind in these sectors" (Haidula, 2018:3). In the 2017/18 and 2018/19 national budget the MOHSS was allocated a mere N\$6.5 billion (six and a half billion Namibian dollars), whereas the Ministry of Education, Arts and Culture was allocated N\$11.9 billion (eleven million nine-hundred thousand Namibian dollars) for the 2017/18 financial year and N\$13 million (thirteen million Namibian dollars) for the 2018/19 financial year (Haidula, 2018:3). His Excellency Dr Nujoma said that although the health sector has seen some progress there was still more than needed to be done (Haidula, 2018:3). He further stated, "The only thing to do is to spend money well. Invest more than half of government's budget on education and health" (Numjoma, 2018:3). The Hon. Minister of Health confirmed that in Namibia over 1.7 million Namibians do not have access to quality health care, and that this predicament is attributed to the high cost of private health care and the quality of public health care (Nashuuta & Kapembwa, 2018). The country's health care system continues to face vast challenges and dominant amongst these are the blatant inequalities in the delivery of health services in the country (Karamata, 2014). Namibia is faced with a worrying contrast between a highly resourceful and advanced private health sector, and a strained public health system (Karamata, 2014).

As previously stated, dementia care is often complex and requires a more comprehensive approach; unfortunately, it is often reported that the implementation of policy directives for person-centred care for older people with cognitive impairment in acute care settings is a challenge; the lack of resources is a threat to dignity promoting care (Heggestad et al., 2015:836); and the fact that many medical professionals lack knowledge of cognitive impairment generally, and dementia specifically, negatively impacts the quality of care people with dementia receive (Grealish, Simpson, Soltau & Edvardsson, 2018:2). For medical staff to promote the dignity of their patients, they need time, support and resources (Grealish et al., 2018:2), which is often limited due to financial constraints. When resources are scarce medical personnel tend to prioritise the physiological or biomedical needs of patients and their psychosocial needs are too often neglected and left unattended (Grealish et al., 2018:2).

Grealish et al. (2018:2) further state that, "...while person-centred care is valued in contemporary hospital settings, providing person-centred care to older people with cognitive impairment may be complicated by the specialist structure of tertiary hospitals that focuses on physical disease presentations and efficiency". Although person-centred care is valued in present-day hospital settings, the specialist structure of tertiary hospitals that tend to focus mainly on physical disease presentations and efficiency makes providing person-centred care to older people with cognitive impairment a challenge (Grealish et al., 2018:2). Due to the financial constraints faced by the MOHSS, the shortage of supplies and staff members, and the lack of mental health care facilities for those in need of specialised mental health services and care are often overlooked, neglected and ultimately avoided.

3.5.1.4 Access to quality health services: inequalities and the need for universal health care

On 7 April 2018, the World Health Day was celebrated globally with the theme of the celebrations being "Universal Health Coverage: Everyone, everywhere" (Nashuuta & Kapembwa, 2018). Universal Health Coverage (UHC) means that everyone can access quality health services, without having to endure poverty to pay for health care; yet, regardless of some advancement, at least half of the world's population still do not have access to essential health services (World Bank, 2018). Attaining UHC has been

a social objective of most nations and is presently a chief health policy priority around the developing world (Bitran, 2014:1). Guided by the UN, as part of the Sustainable Development Goals (SDGs) the global community has committed to try and achieve universal health coverage (UHC) by 2030. The core purpose of universal health coverage is intended to guarantee that every person, everywhere can access vital quality health services without facing financial adversity (Nashuuta & Kapembwa, 2018). UHC is a vital element of sustainable development and poverty eradication, and a fundamental component of any effort to decrease social inequities; it is consequently the hallmark of a government's vow to improve the wellbeing of its citizens (Karamata, 2014).

In 2017, about half of the world's population still did not have full coverage of essential health services and close to 100 million people are still being pushed into "extreme poverty" because they must pay for health care (Nashuuta & Kapembwa, 2018). As in most parts of the world, World Health Day was also celebrated in Windhoek. On the day Hon. Dr. Bernard Haufiku restated that disparities exist in access to healthcare, and this is executed by the existing health financing structure in the country (United Nations Namibia, 2018:3). Regarding the Public Service Employment Medical Scheme (PSEMAS), the Hon. Minister said that reform is needed, and he stated, "we will continue to advance inequality, if we continue to allocate close to NAD 3 billion in public funds to less than 300,000 Namibians, of which only 124,000 make meagre financial contributions through monthly premiums" (United Nations Namibia, 2018:3). This disparity opposes one of the central pillars of UHC which promotes financial protection of the 'poor, poverty stricken, the vulnerable, and the weak members of our community' (United Nations Namibia, 2018:3).

Nashuuta and Kapembwa (2018) report that in 2006 the WHO stated that only 316 000 (three hundred and sixteen thousand) Namibians were covered by medical aid, and that the health care products offered by the private medical aid funds in Namibia are simply too expensive for citizens to afford. Hon. Haufiku suggested a merging of financial resources and 'cross subsidisation and strengthening solidarity' to guarantee that no one is left out of care (United Nations Namibia, 2018:3). During the celebrations, Ms Anita Kiki Gbeho, the former United Nations Development Programme (UNDP) Resident Representative in Namibia, said that in Namibia the

quality of healthcare remains a challenge, and many inequalities are still prevalent in the access to quality care (United Nations Namibia, 2018:3). Ms Gbeho further advised leaders to “recommit to the Sustainable Development Goals (SDGs), specifically Goal 3 ‘Good Health and Well-Being’”, as this would go a long way in improving the country’s health system (United Nations Namibia, 2018:3).

The Ministry of Health and Social Security Commission (SCC) have been instructed to guarantee that Namibia achieves UHC, where one and all receive quality health care irrespective of their economic status (Nashuuta & Kapembwa, 2018; United Nations Namibia, 2018:3). The SCC is mandated by the Namibian government to guarantee universal health through the Social Security Act, No. 34 of 1994, through creating the National Medical Benefit Fund (NMBF) that is anticipated to be realised by the end of 2018 (Karamata, 2018; Nashuuta & Kapembwa, 2018). The goal of this fund is to “provide for the payment of medical benefits to every Namibian employed or unemployed, earning low income or high income, and SCC has confirmed that preparations are at an advanced stage and that the NMBF will be implemented soon” (Nashuuta & Kapembwa, 2018). “Innovations mean little without strong healthcare systems to deliver them” (Dhaliwal, 2018). The Hon. Minister of Health (Haufiku, 2018:3) similarly agrees that UHC will improve the country’s healthcare system, however:

Without proper physical and other health infrastructure, proper medical equipment, adequate human resources for health and sufficient funding of healthcare services, UHC will remain a pipe dream. Universal Health Care will strengthen access to quality healthcare in Namibia and broaden its basis for the good of the population rather than only a few members of society

On 27 November 2017, Ms Anita Kiki Gbeho, the former UNDP Resident Representative in Namibia, said the following:

While poverty has steadily and significantly declined since independence, the same cannot be said about inequality. It is thus crucial to understand the dynamics of inequality and disparities in Namibia and propose possible interventions to address this challenge. Inequality as measured by the Gini co-efficient is currently estimated at 0.572 classifying Namibia as one of the most unequal countries in the world. Between 1993 and 2015, poverty was reduced by 51.3 % while inequality reduced by only 7.4 % (Gbeho, 2017:3).

Given the present inequities in social health delivery in the country, and considering universal trends in health care financing, Namibia cannot continue doing nothing, instead the country should be forced both by integrity and good socio-economic sense to move in the direction of creating a national health care financing system (Karamata, 2018). Globally, these systems have proven to be one of the most effective ways in accomplishing the objectives of universal health coverage (Karamata, 2018), and Namibia government needs to strive to implement universal health coverage which is made available to all Namibians.

3.6 SUMMARY

In this chapter the researcher elaborated on the type of care that people living with dementia require and if these care needs are catered for in Namibia, and she focused on the health care system in Namibia and the extent to which services are available to and accessible by the older population. Furthermore, the researcher elaborated on the fact that the right to physical and mental health is a fundamental human right that each human being needs to enjoy; however, the right to mental health is often neglected or ignored within the Namibian health care system. The Namibian population is rapidly aging, and the number of older people affected by mental health problems have increased. The Namibian health care system is not equipped to deal with the increased demand for quality and comprehensive medical, physical and cognitive needs of people living with dementia. The lack of medical supplies, skilled health care professionals, facilities, knowledge and finances the complex needs of persons living with dementia cannot be met. Unless more is done to educate health care professionals on the symptoms and complex needs of persons with dementia, support family caregivers, and create public awareness of dementia the elderly living with this disease will continue to fall through the gaps in the Namibian health care system.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 INTRODUCTION

The research question that this study aims to answer is: What are the experiences of adult children, who made the decision to place their parents diagnosed with AD in one of only two dementia care clinics in Namibia? Therefore, the goal of this research study is to explore and describe the experiences of adult children, who made the decision to place their parents diagnosed with AD in a dementia care institution in Namibia.

The purpose of this chapter is to provide an outline of the research methods that were adopted. In this chapter the researcher will discuss the various aspects considered and applied within the qualitative approach, including the type of research most suitable for the purpose of the study, the criteria for inclusion in the study, who the participants were, and why and how they were sampled; the research design that was chosen for the purpose of data collection and the reasons for this choice; the data collection method that was applied and the procedures followed to conduct the study. Furthermore, the researcher will discuss the process of data analyses, which will involve a detailed discussion of the steps provided as a guideline by Creswell (2009:407-409). To conclude the chapter, the researcher will discuss the challenges pertaining to trustworthiness and how she dealt with these challenges to ensure that the trustworthiness of this study was not implicated.

4.2 RESEARCH APPROACH

Social science research is universal and affects one's daily life; and the knowledge and principles of social science research is used, directly or indirectly, in the everyday engagement with individuals, family, friends and the community (Neuman, 2014:1). Social scientists apply various scientific methods to transform "ideas, hunches, and questions, sometimes called hypotheses, into new knowledge" (Neuman, 2014:16). This type of research is conducted through adopting either a quantitative or qualitative approach and both approaches use several research techniques to gather and analyse empirical data (Neuman, 2014:16). Although both approaches are equally significant

and share core scientific principles (Neuman, 2014:17), for this study the qualitative research approach was most applicable.

Qualitative research uses a true-to-life approach that strives to understand phenomena about “persons’ lives, stories, and behaviour including those related to health, organizational functioning, social movements, or interactional relationships” (Cypress, 2015:356). Qualitative research methods are more likely to tap into the deeper meanings of specific human experiences and are expected to “generate theoretically richer observations” (Rubin & Babbie, 2013:40). Qualitative researchers describe perceptions on several phenomena; phenomena are the “experiences that compromise the lives of humans” (Grove, Gray & Burns, 2015:67). An experience is seen to be unique to the “individual, time and context, which is why qualitative researchers describe a phenomenon from the perspective of the person who is experiencing the phenomenon” (Grove et al., 2015:67). Generally, qualitative research is more inclined to using a wide range of evidence and discovering new questions (Neuman, 2014:39).

Research on AD is widespread and easy to come by, however, not much has been said about the impact that an AD diagnosis has on the family members of those living with this disease. Many qualitative researchers rely on personal beliefs and experiences to identify a topic of interest or importance (Neuman, 2014:20); therefore, the researcher chose to dive into this topic not only because she has been exposed to the grim reality of this consuming disease in her personal life; but also because, worldwide research has focused primarily on the scientific aspects of the disease and caring for someone living with AD, with little to no attention given to the impact that this disease has on those closest to the diagnosed individual.

One may empathise with a family member whose loved one has been diagnosed with AD but have only partial appreciation for the perceptions of the family member (Grove et al., 2015:67). Thus, in order for family members and friends to provide support, maintain relationships and care for their loved one impacted by AD, it is essential that they be informed and educated on what it means to have AD, that they attempt to understand the perceptions of their loved ones, be informed on the changes they can

expect to encounter; and how to deal with the tremendous sense of continuous loss that this disease brings.

Qualitative research is a systematic and scholarly approach which is used to describe life experiences, situations, cultures, and social processes from the perspectives of the person's involved (Gray, 2017a:62, Grove et al., 2015:67). Unlike quantitative researchers, qualitative researchers gain insights not by assessing concepts or studying statistical relationships; but instead, they increase the understanding of a phenomenon from the view point of the people experiencing it (Gray, 2017a:62). The qualitative approach enables researchers to focus on everyday events that occur naturally in ordinary settings. By exploring the individual's perception of these events, qualitative research can generate rich descriptions of the experiences of individuals, and this in turn allows for the exploration and understanding of the "depth, richness, and complexity inherent in the lives of human beings" (Gray, 2017a:62, Grove et al., 2015:67). By adopting the qualitative approach, the researcher aims to stress the depth of understanding, try to subjectively tap into the deeper meanings of human experiences, and intends to generate theoretically rich observations (Rubin & Babbie, 2013:47). The researcher further aimed to gain a better understanding of the impact that an AD diagnosis has on the emotional, physical and psychosocial aspects of the adult child. Through exploring the phenomenon of an AD diagnosis and the impact it has on the entire family system, the researcher anticipated to gain a better understanding into the needs of adult children who have a parent living with AD and establish how professionals and service deliverers can adequately support these individuals.

Instead of searching for a one-reality-one-truth, researchers who are committed to a qualitative approach believe that individuals actively participate in social actions, and through these interactions that occur, based on previous experiences, individuals come to know and understand phenomena in diverse ways (Streubert, 2011a:20). Because people understand and experience life encounters differently, qualitative researchers do not describe to one truth, but rather, to many truths (Streubert, 2011a:20).

Furthermore, qualitative researchers seek to provide a holistic picture of the phenomena guided by the following beliefs (Grove et al., 2015:67):

1. There are multiple, constructed realities because meaning is subjective (created by individuals) and intersubjective (created by groups).
2. Knowledge is co-constructed by the person involved in an interaction.
3. Human behaviour, such as words and actions are choices influenced by the past and the present, as well as by the physical, psychological, and social contexts of the behaviour or experiences.
4. Time and context influence individual and group perspectives.

Qualitative research may also be based on constructivism, the belief that there are multiple realities or truths that need to be considered when fully trying to understand a situation; and from this approach it is believed that a person constructs reality within a context of time and place (Gray, 2017a:63, Streubert, 2011a:20). The reasoning process which qualitative researchers use, involves putting pieces together perceptually to make wholes, and it is through this process that meaning is produced. It is likely that many meanings can be produced as perception varies with the individual (Grove et al., 2015:67). Commitment to participants' viewpoints is another characteristic of qualitative research (Streubert, 2011a:21), and by using interviews, observations, and artefacts researchers are grounded in the real life of study participants.

In this study, the researcher was interested in the phenomenon of AD, with a specific focus on the subjective experiences of adult children living in Namibia, in dealing with the various life changes brought about by an AD diagnosis in their older parents. The researcher therefore made use of the qualitative approach to truly explore and understand the experiential world of adult children, with the specific focus on their individual experiences around the impact a diagnosis of AD has had on their lives.

Furthermore, this research study was explorative in nature. Exploratory research is conducted to "gain insight into a situation, phenomenon, community or individual", with the necessity of such a study arising due to a need of basic information on a new area of interest (Fouché & De Vos, 2016:95). Much of social work research is focused on exploring a topic, especially so when the researcher is examining a new interest (Rubin

& Babbie, 2013:50). Although much research has been done in the field of dementia, research about dementia in Namibia is scarce. Berrie Holtzhausen, founder of ADN and one of the few people who have conducted research about this disease and the Namibian context, states that in Namibia, people with dementia are still seen as “zombies, waiting for death” or even worse, as the subjects of witchcraft (Holtzhausen, 2012). Holtzhausen (2012) continues to state that families who need to take care of people with dementia often struggle due to the absence of resources and a lack of knowledge.

When a researcher aims to answer a “what” question, an exploratory study is most likely to be conducted (Fouché & De Vos, 2016:95). The researcher aimed to gain insight into the effect of dementia on the adult children of the diagnosed parents, focusing on the experiences of the parent-child relationship, as well as the experiences of health care available to older persons diagnosed with dementia in Namibia.

4.3 TYPE OF RESEARCH

For the purpose of this study the applied research perspective was most suitable. Also known as practical research, applied research embraces scientific investigations which are conducted to generate knowledge that will have a direct effect or advance clinical practice (Grove et al., 2015:35). Applied research is used when the researcher is interested in addressing a specific concern or attempts to solve specific problems, and is designed to make specific recommendations and offer practical and concrete solutions to a problem (Brink, van der Walt & van Rensburg, 2014:100; Neuman, 2014:27); this type of research is aimed at helping researchers accomplish tasks or aims to solve specific policy problems (Fouché & De Vos, 2016:95). The findings from applied research can be instrumental to policy makers as a foundation for making changes to address health and social problems (Grove et al., 2015:35).

Furthermore, applied research places a strong emphasis on resolving problems, making decisions, and/or envisaging or controlling outcomes in real-life practice situations (Grove et al., 2015:35). The purpose of applied research, unlike basic research, is to answer questions, not general theoretical ones (Sutherland, 2017:42). Applied research is largely descriptive in nature, and its chief advantage is that it can

be applied instantly after the results have been attained. Applied research is thus problem-orientated and focused on a well-defined and purposeful end (Brink et al., 2014:100).

In late 2013, the G8 summit acknowledged dementia as a key public health issue and made a commitment to establish a cure for dementia by 2025 (Cahill, Pierce, Werner, Darley & Bobersky, 2015:255-256). At this summit, it was further argued that responding effectively to dementia required a response from all sectors of society, and accordingly, countries were advised to endorse various forms of civic engagement on dementia awareness and contribute to the prevention of dementia (Cahill et al., 2015:256). At that time, the British Prime Minister of the United Kingdom, David Cameron, stated that many people do not understand dementia, and as a result, they lack the necessary knowledge required to help and support those living with this progressive illness (Cahill et al., 2015:256). Cahill et al. (2015:256) continue to state that raising public awareness of dementia is crucial for optimising care and ultimately augmenting the quality of life of people diagnosed and their caregivers.

Hartman (2015) asserts that although Namibia has laws that take care of the elderly, they are old, frail and unable to depend on hospital services due to the country's lack of policy. Applied research is used to solve problems encountered in practice (Botma, Greef, Mulaudzi & Wright, 2016:53), such as the lack of support for family members of those living with AD and the absence of affordable quality care facilities. Applied research increases scientific and technological knowledge by adding knowledge in "decision making, policy analysis and community development" (Botma et al., 2016:53). By focusing on the applied research perspective, the researcher hoped to magnify the absence of a frail care policy in Namibia and highlight the importance of support services for family members affected by AD.

Although this research was done on a small scale, the researcher was particularly interested not only on the impact an AD diagnosis has on the adult child, but also the extent of care services available in Namibia to those diagnosed with this dreadful disease. Currently there is only reference of two care facilities, which cater for the specific and special needs of those, diagnosed with AD in Namibia; and only limited reference is made to the personal experiences of adult children in knowing about,

identifying and choosing a care facility in Namibia for their older parents diagnosed with AD. Not all Namibian families are able to afford the specialised care provided by ADN Care Farm; and as such it is essential that the Namibian Government be made aware of the increasing number of people living with AD, so that affordable and effective facilities can be budgeted for and developed to ensure that all persons living with dementia have access to good care facilities.

An AD diagnosis affects an entire family system, a community and society, not just the individual who is subjected to the diagnosis. In order to provide effective and sufficient support to the family system, it is important to know in which areas family members need most support. Thus, by focusing on the personal experiences of adult children in Namibia, this study aimed to help identify the physical and emotional needs of the adult child and the older parent diagnosed with AD, and it also assisted in shedding light on the absence of Namibian health care facilities, explicitly designed to meet the specific and special needs of older persons suffering with degenerative dementias, and the need for awareness raising about AD in Namibia. This study will further be used by the researcher to make the Government of the Republic of Namibia, although on a very small scale, aware of the lack of quality health care facilities for the elderly. Based on the research findings, the researcher's aim is to apply the research findings in the development of a dementia care facility.

4.4 RESEARCH DESIGN

The research design most applicable for this study was the phenomenological design. Phenomenology originated from the work of Alfred Schutz who aimed to describe how the life world, which refers to "a person's conscious experience of everyday life and social action", of subjects is created and experienced by them (Delport, Fouché & Schurink, 2016:316). The phenomenological approach to research is intended to describe what a person's life world comprises of, or more precisely, what perceptions and structures of experience give form and significance to it (Delport et al., 2016:316).

Phenomenological studies observe human experience through the accounts that are provided by the people involved. These experiences are known as 'lived experiences (Brink et al., 2014:121). Phenomenological researchers ask: "*What is it like to*

experience this or that?” (Brink et al., 2014:121); and seeing that being a person is self-interpreting, the person himself or herself is the only reliable source of information to answer this question (Grove et al., 2015:69). Therefore, the purpose of phenomenological research is to describe what people experience concerning certain phenomena, as well as how they understand these experiences or what significance the experiences hold for them (Brink et al., 2014:121, 122; Sutherland, 2017:87).

The researcher attempted to describe the phenomenon as accurately as possible, refraining from any pre-given framework, but remaining true to the facts (Delpont et al., 2016:316). Delpont et al. (2016:317) stress the importance of researchers distancing themselves from the predeterminations about the nature and essence of experiences and events in the everyday world. Prior to the enquiry process it is imperative that researchers recognise and set aside any preconceived beliefs, biases and sentiments that they might have with regards to the phenomenon being studied; this is also known as “bracketing” (Brink et al., 2014:122; Delpont et al., 2016:316; Grove et al., 2015:69). Although the researcher has experienced the tremendous loss associated with AD, she does not assume that the participants experienced the same feelings or that it holds the same meaning for them. The researcher has experienced feelings of anger, sadness, hopelessness and unbelief in the face of an AD diagnosis. However, she noticed and set aside her own experiences as she aimed to understand what significance and impact an AD diagnosis has on the adult child from their perspective. An AD diagnosis can be devastating, and thus a phenomenological design allowed the researcher to focus on and understand the personal experiences of individuals who have had to deal with such a diagnosis first hand.

Schwartz and Scott (2010:404) assert that whereas some older family members are living independent, healthy and active lives, some unfortunately are frail and in need of special care. In this study the researcher’s population was a group of adult children, who due to their parents’ frailty and need for specific care, willingly or forced by circumstances, placed their parents in an institution which provides around the clock, specific and special care for those diagnosed with dementia. The decision how to best care for an elderly parent can be a difficult decision (Schwartz & Scott, 2010:407) and the family can become emotionally and physically drained by the extensive care required for a person with dementia (Santrock, 2015:560). Very often adult children

have feelings of regret and guilt for deciding to place their parents in an institution, and these feelings can make it difficult to have a healthy relationship with a parent. The researcher was interested in exploring and discussing the effect that an AD diagnosis in parents have on adult children by focusing specifically on the adult child's personal, first hand experiences in living with the AD diagnosis and relating to the diagnosed parent they were forced to institutionalise. The phenomenological design aided the researcher to explore these intimate and personal experiences.

4.5 RESEARCH METHODS

4.5.1 Study population and sampling

The term population refers to the whole group of persons, objects or substances that is of interest to the researcher and that meets the specific criteria that the researcher is concerned with (Brink et al., 2014:130; Grove et al., 2015:46). The criteria set out for this study is: participants need to have a parent/s who was diagnosed with AD, and their parent/s must be a current or past resident of the ADN Care Farm. Therefore, the population in focus of this study is a group of adult children, both male and female, whose parents are or have been residents at the ADN Care Farm. Gender and cultural partiality and insensitivity can impair the methodological quality of a study and therefore the validity of its findings (Rubin & Babbie, 2013:298) and therefore, the researcher attempted to have an equal number of male and female participants. Although AD is not confined to residents of the ADN Care Farm, interviewing all adult children of all the dementia diagnosed older parents in Namibia would be nearly impossible. The population of interest to the researcher was the adult children of older parents living with AD; however, the researcher has set "boundaries with regards to the elements or participants" (Brink et al., 2014:131) and as such, the researcher studied a subset of the larger population (target population), namely the adult children of current or past residents at the ADN Care Farm. Some of the residents of the care facility have passed on, but the experiences of their adult children are still valid and provided the researcher with rich data.

4.5.1.1 Sampling

A sample refers to a small number, part or a fraction of a whole, of cases a researcher selects from a larger group to participate in the study (Brink et al., 2014:131, 132; Neuman, 2014:246). The researcher selected several cases from a large group, which were examined in detail, and the knowledge gained from studying this set of cases was used to gain a greater understanding of the larger group (Neuman, 2014:246). Sampling is referred to as the process during which the researcher selects a portion or smaller number of units of a population to obtain information regarding a specific phenomenon, which is representative or has characteristics of that total population (Brink et al., 2014:132; Strydom, 2016:223, 224). In qualitative studies, Neuman (2014:247) continues, researchers sample aspects or features of the social world, and these aspects or features highlight the key dimensions or processes in complex social life. In qualitative sampling the goal is to ultimately deepen the understanding of larger processes, relationships, or social scenes (Neuman, 2014:247). In this study, the researcher was interested in the experiences of the adult children of older parents diagnosed with AD, specifically within the Namibian context.

To ensure that every person in the target population had the prospect to be chosen for the sample, each person in the population had to be identified. To achieve this goal, the researcher obtained a list of every member of the target population by using sampling criteria to define membership; “this listing of members of the population is referred to as the sampling frame” (Grove, 2015a:336).

The sampling frame refers to “a list of cases in a population, or the best approximation of them” (Rubin & Babbie, 2013:252), and it provides the researcher with a temporal boundary when selecting participants. A good sampling frame is essential to ensure accurate sampling, as any mismatch between a sampling frame and the conceptually defined population can result in errors (Rubin & Babbie, 2013:252). The sampling frame further refers to the process during which the researcher identifies and lists the members of the population and once completed, the researcher uses a sampling plan to select subjects from the sampling frame (Grove, 2015a:336). The sampling plan refers to the approaches that the researcher uses to select a sample for the study and is essential to the study as it improves representativeness, reduces systematic prejudices,

and reduces sampling error; the sampling approaches planned by the researcher ensured that the above mentioned tasks were accomplished and that sample selection is improved (Grove, 2015a:336). When using a sampling plan, the researcher may use of probability (random) or non-probability sampling methods (Grove, 2015a:336).

4.5.1.2 Non-probability sampling

As previously discussed, it would have been impossible for the researcher to identify and conduct interviews with every adult child who has a parent living with AD in Namibia. Therefore, the researcher used a sampling frame to identify a specific target population within Namibia, namely the adult children whose parents are or have been residents of the ADN Care Farm within the period of 2011 to 2016, which provided her with a temporal boundary to select participants (Rubin & Babbie, 2013:252). Once the target population was identified, the researcher used a sampling plan to select a sample from the target population who participated in the research study.

The ADN Care Farm is not limited to only older persons living with AD. Dementia is the umbrella term which refers to an assortment of diseases and disorders that develop when nerve cells in the brain die or no longer function normally (Thies & Bleiler, 2012:132). AD is only one of the diseases that lead to dementia. The ADN Care Farm currently cares for individuals living with Front-Temporal Dementia, Lewy-Body Dementia, Vascular Dementia and AD, which are all diseases that cause dementia. The researcher was particularly interested in the adult children of older persons living with AD, as it is the most common form of dementia and as such the entire population, all the adult children whose parents are residents of the ADN Care Farm, did not have an equal chance of being selected for the study. The participants for the research study were limited to older children whose parents are residents of the ADN Care Farm and are living with AD, therefore, the researcher employed non-probability sampling.

In non-probability sampling, not every person of the population has the prospect to be chosen for the study (Grove et al., 2015:263); and as such, non-probability sampling is a type of sampling that may or may not truthfully represent the population (Brink et al., 2014:139). This type of sampling allows the researcher to study a fraction of an entire population when it is impossible to reach the entire population (Brink et al.,

2014:139; Grove et al., 2015:263). For example, in this study the researcher focused on a specific group of adult children of older parents living with AD instead of the entire population of adult children in Namibia. Non-probability sampling involves using procedures to select a sample that is not based on random selection (Rubin & Babbie, 2013:171) and this requires that the researcher uses judgment and chooses those participants who know the most about the phenomenon, and who are able to express and explain their experiences and perceptions of the phenomenon being studied (Brink et al., 2014:139).

4.5.1.3 Purposive sampling

The researcher made specific use of purposive sampling, which is a type of non-probability sampling (Rubin & Babbie, 2013:172). Purposive sampling is also referred to as judgemental or purposeful sampling (Brink et al., 2014:141; Grove, 2017:345; Grove et al., 2015:270; Strydom & Delpont, 2016:392); selection of participants is based on the judgement of the researcher. The researcher intentionally selects participants for the study who are representative, or form part of the phenomenon being studied, or who have first-hand experience with the question and phenomenon at hand (Grove et al., 2015:270; Brink et al., 2014:141; Streubert & Carpenter, 2011:29). In purposive sampling, the researcher tends to choose information-rich cases from which she can obtain in-depth information for her study, and which can teach her a great deal about the central focus or purpose of the study (Grove, 2017:345; Grove et al., 2015:270). It is crucial that the pre-selected criteria for the selection of participants is clearly identified and formulated (Strydom & Delpont, 2016:392).

As the head of the ADN Care Farm, Mr. Berrie Holtzhausen has a record of names of all the people who have been residents at the facility, along with the details of their relatives. The only criteria that Mr. Holtzhausen was asked to consider, in order to prepare a final list of possible participants, were the names and contact details of the adult children who placed their older parents diagnosed with AD in the ADN Care Farm between 2011 and 2016, which served as the researcher's sampling frame. Some of the residents might have been placed in the facility by spouses or other relatives; however, the researcher was interested in the experiences of the adult children of the residents. The criteria for the purposive sampling were:

- Both male and female adult children of ADN Care Farm residents.
- Adult children of parents placed in the facility between 2011 and 2016.
- Adult children able to converse in English and Afrikaans.
- Adult children willing to participate in the research study.

Mr. Holtzhausen made initial contact with the adult children who fitted the above criteria to inquire whether they were willing to partake in the study, and if yes, whether he could provide the researcher with their contact details. If they agreed, the researcher contacted the participants who were willing to partake in the study. Mr. Holtzhausen is the founder of the ADN Care Farm, and each adult child has been in direct contact with him before and during their parents' residence in the facility. Each of the possible participants identified by Mr. Holtzhausen know him personally, and the researcher believed if he made initial contact and explained the basic purpose of the study, the participants would feel more assured and less reluctant to participate. Eleven (11) participants were identified and selected for this research study. Furthermore, the researcher conducted an in-depth unstructured interview with Mr. Holtzhausen on 20 January 2018 to explore his perceptions regarding the experiences of adult children who have had to place their demented parents in the ADN Farm in Swakopmund, as well as his perception on the availability of services and care facilities, for people living with dementia, within Namibia.

4.6 DATA COLLECTION

The data gathering technique most suited for this study was the open-ended, unstructured interview, also referred to as the in-depth interview (Botma et al., 2016:206; Greeff, 2016:348). Unstructured interviews are often described as interviews that take the shape of purposeful informal conversations (Brink et al., 2014:158; Gray, 2017b:259; Streubert & Carpenter, 2011:34); informal conversations purposely intended to understand a specific phenomenon from the participant's viewpoint, and to dive into the participant's lived world (Botma et al., 2016:207). At the basis of unstructured interviewing is an interest in understanding the experience of other people and the meaning they make of the experience (Greeff, 2016:348). The purpose on an in-depth interview is not to get answers or test a hypothesis. Instead,

the primary focus of this type of interview is to try and truly understand the specific experience of the participants and the meaning they attach to this experience (Botma et al., 2016:207); these interviews can produce more in-depth information on the participant's opinions and perceptions than can be gained through any other data gathering technique (Brink et al., 2014:158).

Unstructured interviews have limited structure; and unlike other interviews where the researcher has a specific set of questions that must be asked in particular words and order, the researcher is led by a single broad question followed by probing questions that encourage participants to elaborate on their experiences and perceptions (Botma et al., 2016:207; Brink et al., 2014:158; Rubin & Babbie, 2013:123). In this study the researcher had one broad question that was posed to each participant, "*You made the decision to place your parent in the ADN Care Farm. What led to you ultimately making this decision?*" Once the participant had answered the primary question, the researcher used a few probing questions to better understand the impact that an AD diagnosis has had on each adult child. Unstructured interviews are often the preferred interview method for phenomenology (Gray, 2017a:256) and therefore, this data gathering technique was considered most suitable for the study, as the researcher was interested in listening to and understanding the experiences of the adult children from their point of view.

Although the unstructured interview is often dismissed as lacking unbiased data, it is nevertheless, a type of interview, which the researcher uses to prompt information to achieve understanding from the participant's point of view or situation (Brink et al., 2014:158; Greeff, 2016:348). In-depth interviews are interactional events in which the researcher is engaged, rather than objective or detached (Botma et al., 2014:207). These types of interviews imply readiness on the part of the researcher to understand the participant's response to a question in the wider context of the interview (Greeff, 2016:348). The researcher created a relationship with participants by listening attentively, showing interest, and respect for what they are saying (Botma et al., 2014:208). Once participants realised that the researcher was truly interested in understanding their experiences (Brink et al., 2014:158), trust was established, and participants allowed the researcher into the more intimate parts of their worlds.

Unstructured interviews provide the opportunity for greater autonomy in the answers provided, and researchers who use unstructured interviews usually incorporate open-ended questions which allow participants the opportunity to describe their experiences (Streubert, 2011b:35, 36). During in-depth interviews researchers make use of an interview guide, rather than a rigid schedule of questions and an audio or video recorder to record the interview, allowing them to concentrate on the connection and communication with the participant without missing out on important information. Recordings allow for a transferrable, repeatable resource that allows several hearings or viewings (Gray, 2017b:260; Streubert, 2011b:34), and allows the researcher to produce accurate verbatim transcription of the data (Streubert, 2011b:34). The researcher made use of a digital recorder during the interview with each participant. Each participant was asked to sign an informed consent form, giving the researcher the permission to record the interview. Each recording was transcribed during the process of data analysis. Five of the eleven participants reside outside of the capital city, and the researcher travelled to each participant to conduct the face to face interviews with each participant. The duration of the interviews was between 23 minutes and one hour and eighteen minutes.

4.6.1 Pilot study

Qualitative studies are often preceded by a pilot study, which is implemented to test the practical aspects of a specific study (Brink et al., 2014:174; Grove, 2015c:54). Completing a pilot study is a crucial step that avoids difficulty later when the concluding steps of the research process are implemented (Gray, 2017c:508). A pilot study is referred to as “a feasibility study that comprises small-scale versions of the planned study, trial runs of planned methods, or miniature versions of the anticipated research in order to answer a methodological question(s) and to guide the development of the research plan” (Kim, 2010:191). Pilot studies are often implemented with the primary purpose of generating tentative exploratory or descriptive information (Rubin & Babbie, 2013:186). A pilot study is a smaller version of a planned study executed with the same research population, and is conducted to perfect the study sampling process, treatment, and plans for data collection and analyses (Grove, 2015c:54; Grove et al., 2015:45). Primarily, the aim of a pilot study is to determine whether the applicable data needed for the study can be acquired from the participants (Strydom & Delpont,

2016:394-395). Pilot studies can further be used to self-evaluate one's willingness, ability, and commitment as a qualitative researcher and in this sense, a pilot study can be used to train qualitative researchers and to improve the credibility of a qualitative study (Kim, 2010:193).

In qualitative research, the pilot study lets the researcher focus on particular areas that may have been vague beforehand or to test specific questions; and by testing the nature of questions in an interviewing schedule in the pilot study, the researcher is able to make alterations with the aim of ensuring quality interviewing during the main investigation (Strydom & Delpont, 2016:395).

Whilst preparing for this study, two primary concerns arose. Firstly, the researcher planned on making use of in-depth interviews, a primary method of data collection within the phenomenological design. This method of data collection appeared to be most applicable as the researcher was interested in the personal, intimate experiences of adult children, based in Namibia, whose parents were diagnosed with dementia. The researcher had to ask herself, "what is the likelihood that someone who willingly or forced by circumstances placed their older parent diagnosed with dementia in a care facility?" and more importantly, "what is the likelihood that they will share their most personal experiences with a stranger?" Secondly, the researcher intended to conduct her interviews in an unstructured way, which meant that she would have only one or two leading questions followed by a few probing questions. Again, the researcher needed to structure her questions in a way that would encourage participants to share rich information, and she had to ask herself, "what will be my leading questions and how will I probe the participants to share more of their experiences and perceptions?" Researchers are often over-hasty to complete their main investigation, and as a result, they neglect the pilot study (Strydom, 2011a:236). Based on the two concerns identified, the researcher found it of paramount importance to conduct a pilot study. The pilot study assisted the researcher in:

- Determining how she was to approach people who have had to deal with a dementia diagnosis and ask them if they were willing to share their personal and intimate experiences with her; and how she would ensure them that the information they share with her would be treated with respect and confidentially.

- Establishing what information about the purpose of the study participants needed to hear for them to have felt comfortable enough to participate in the study.
- Testing her main and probing interview questions in an attempt to establish whether they elicited information rich responses; and if not, how she had to tweak and restructure her questions to ensure that she collected detailed information from participants.
- Correcting any misunderstandings or misinterpretations that arose as a result of the type or structure of the questions asked.

The researcher had only one participant for her pilot study, and once the researcher completed the pilot study, she established that the questions she asked were adequate in eliciting information-rich responses from the participants, or answers that assisted her in answering the research question of her study and as such she made no adjustments to her interview questions but added only a few more probing questions. The researcher also established that participants would feel more inclined to partake in the study if they were informed on what the primary purpose of the study was, how the information they shared would be used in the study, how their identity and interest would be protected, and whether they would be allowed to receive a copy of the study. The researcher believed that she ensured that all participants would feel protected and that they would be well informed of the purpose of the research study.

The researcher chose to include the content of the pilot interview in the main study as the interview produced personal and information-rich data, which assisted the researcher in answering the main research question.

4.6.2 Data analysis

Data analysis in qualitative research is the practice of “inductive reasoning, thinking, and theorising”, and it can be treated as both a science and an art (Schurink, Fouché & De Vos, 2016:399). In quantitative research data analysis does not begin until all data has been collected (Brink et al., 2014:193). This is however not the case for qualitative research. In qualitative research, data analysis and data collection occur coherently; the researcher attempts to collect, manage and understand a mounting bulk of data simultaneously (Botma et al., 2014:220; Grove et al., 2015:88); there is no

exact point at which data collection ends and analysis commences (Botma et al., 2014:220). Data analysis in qualitative studies often involves scrutinising a substantial amount of data in the form of text, and this makes the analysis process extremely time consuming (Brink et al., 2014:193). During the process of data analysis, a range of investigative approaches are used that include understanding the data by arranging, classifying and reducing them to more manageable quantities, and then exploring ways to reconstruct them (Schurink et al., 2016:399). Unlike in quantitative research, data analysis in qualitative studies is a continuing process which involves recurrent reflection of the data, the asking of investigative questions, and writing of memos throughout the study (Schurink et al., 2016:401); it is often described as a 'hands-on process' during which the researcher becomes totally immersed or dwells in the data collected (Brink et al., 2014:193). For this study, the researcher immersed herself in the data and obvious themes from the onset of data collection.

The purpose of data analysis is "to preserve the uniqueness of each participant's lived experience while permitting an understanding of the phenomenon under investigation"; this process usually commences with the researcher listening to the participant's verbatim transcriptions and is followed by reading and rereading the verbatim transcriptions (Buxton, 2011:92). Neuman (2014:477) asserts that data analysis involves thoroughly classifying, intergrating and scrutinising the data to search for and identify patterns and relationships within the collected data. Through the process of data analysis researchers connect data to concepts, advance generalization and identify broad trends or themes (Neuman, 2014:477).

Most qualitative researchers make use of a sequence of common steps to analyse their data, which usually commences at the start of the data collection phase. Breaking down data into steps aids the researcher in better understanding it (Brink et al., 2014:193). The researcher will provide further discussion on data analysis by elaborating on the following steps, which she used as a guide to analyse the data collected (Creswell, 2009:407-409).

Step 1: Planning for recording date

In qualitative research, data obtained from interviews are recorded either during or immediately after the interview; and these recordings may be in the form of handwritten notes, audio or video recordings (Grove, 2015b:405). Recording the events and experiences of the participant during the interview allows for a much more detailed and accurate record, and it ensures that the researcher is focused on what the participant is communicating both verbally and non-verbally (Greeff, 2016:348, 359). It is essential that the researcher obtains the permission of the participant before recording the interview, and the participant can ask for a copy of the recording after the interview (Greeff, 2016:359).

Once the researcher obtained the informed consent of each participant, she used a digital recorder to ensure that each interview was accurately recorded, and that no experience shared by the participant was missed. Each recorded interview was stored in a folder specifically created for this study, on the researcher's computer.

Step 2: Data collection and preliminary analyses

In planning for the collection of data the researcher is guided by five important questions, namely: "What? How? Who? Where? When?" (Schurink et al., 2016:405; Brink et al., 2014:147). To answer these questions the researcher needs to establish: what type of information is needed to answer the research question; what research instrument will be used to gather the data; who will collect the data; in what setting the data will be collected; and when the data will be collected (Brink et al., 2014:149 – 150). Before the data collection process commenced, the researcher established that she would make use of a digital audio recorder, be the one collecting all the data, the interviews would take place in a quiet and private setting, and that the data would be collected over a period of six months. To ensure that the "what" question was answered and adhered to throughout the data collection process, and that the information collected answered the research question, the researcher made use of field notes. Field notes refer to written interpretations of what the researcher hears, sees, experiences, and during collecting and reflecting on the data gathered (Schurink et al., 2016:406). Field notes assist the researcher in reflecting on the data being analysed,

in other words it assists the researcher in establishing whether the research question is being answered, highlighting themes that are emerging, and making connections between pieces of data (Schurink et al., 2016:406).

In qualitative research, data analysis demands a dual approach (Botma et al., 2016:220; Rubin & Babbie, 2013:336; Schurink et al., 2016:405). The first comprises of data analysis in the field during data collection, whereas the second comprises of data analysis away from the field succeeding a period of data collection (Botma et al., 2016:220; Gray, 2017b:274; Schurink et al., 2016:405). Approaches such as phenomenology, do not merely focus on analysing the subject matter, but it refers to the “dwelling with the data” (Grove et al., 2015:89) and also emphasises the collecting and presentation of data in such a way that allows the subjects to “speak for themselves” (Gray, 2017b:269; Schurink et al., 2016:405). To build a comprehensible interpretation of the data collected, it is important that data collection and data analysis complement one another (Schurink et al., 2016:405). During data collection, ideas about directions for analysis will occur, patterns will appear, and possible themes will take shape (Schurink et al., 2016:405). Thus, the researcher used field notes to identify possible commonalities or possible themes after every interview. Any gaps found in the interviews could lead the researcher to conduct follow-up interviews if necessary, in order to clarify or obtain more depth in the responses.

Step 3: Managing the data

Managing one’s data, including treating field notes and interviews as gold, is an important aspect of data analysis. Once the data collection process begins, the researcher begins to gather huge quantities of data that needs to be carefully and securely stored (Gray, 2017c:509; Grove et al., 2015:88). How the researcher managed her data would greatly affect the ease with which she analysed the data, and therefore storage and retrieval were important considerations throughout the research process (Streubert & Carpenter, 2011:43). In qualitative research, large amounts of data can be stored on computers, and various computer-based programs are available for this purpose (Grove, 2017c:509; Grove et al., 2015:88; Streubert & Carpenter, 2011:43). An organisational plan is needed to ensure that data is stored securely, which involves safeguarding computers and storage devices to guarantee

confidentiality, and it is strongly recommended that data files be securely stored in more than one location to prevent the loss of data (Grove et al., 2015:88).

To ensure that each audio recording would be safely and securely stored, the researcher saved the recordings in a specific folder on her computer, saved each recording on her external hard drive, and uploaded each file onto her Dropbox account. Uploading files onto a Dropbox account ensures that if the computer or external hard were damaged beyond repair, the files would still be secure and accessible.

In qualitative research, transcribing verbal data into written data is a tedious component, and these transcriptions serve as major data sources in qualitative studies (Botma et al., 2016:214; Gray, 2017b:268). When audio recordings are transcribed it allows the researcher to review the data visually, therefore, it is important that the researcher ensures that verbatim transcriptions are truthful and that they authentically mirror the totality of the interview (Botma et al., 2016:214). Each recorded interview was transcribed, and the researcher ensured that the verbatim transcriptions were accurate by listening to each recording again whilst reading through the transcription. The data was properly labelled, according to dates, place and interviewee identifying information. Typing and organising handwritten field notes offer another opportunity to immerse oneself in the data in the transition between fieldwork and full analysis (Schurink et al., 2016:408). The researcher used a hard copy of the data during the analysis and a copy for additional notes and comments.

Step 4: Reading and writing memos

Researchers develop memos in order to record perceptions or ideas associated with notes, transcripts, or codes; and these memos move the researchers towards theorising, and they are “conceptual rather than factual” (Gray, 2017b:273). Memoing is defined as, “a qualitative data analysis technique used at several stages of data processing to capture code meanings, theoretical ideas, preliminary conclusions, and other thoughts that will be useful during analysis” (Rubin & Babbie, 2013:339).

The researcher wrote memos and short notes in the margins of her field notes and transcripts. The memos consisted of short phrases, ideas or key concepts (Schurink

et al., 2016:409). Furthermore, the researcher used a mixture of three kinds of memos, namely code notes, theoretical notes and operational notes (Schurink et al., 2016:410; Rubin & Babbie, 2013:339). Schurink et al. (2016:410) differentiate between the above-mentioned memos. Code notes are used to identify code labels and their meanings, which the researcher used in the analysis; theoretical notes are notes that the researcher used to critically reflect on what took place, what she experienced, and reflections and meanings of concepts; and operational notes are detailed notes on circumstances relevant to understanding the data. These memos assisted the researcher to explore the initial database.

Step 5: Generating categories and coding the data

Coding is the “process of reading the data, breaking text down into subparts, and giving a label to that part of the text” (Grove et al., 2015:89); it involves arranging the data collected into chunks or sections of text prior to bringing meaning to the data (Botma et al., 2016:224). Coding further involves taking text data collected during data collection, and segmenting the words, phrases, sentences and paragraphs into categories, whilst labelling those categories with a term grounded on the language of the participant (Botma et al., 2016:224). Codes could be “(a) developed only based on the emerging information collected from participants, (b) by using predetermined codes and then fitting the data to them, or (c) by using some combination of predetermined and emerging codes” (Botma et al., 2016:225).

Researchers who adopt a qualitative approach analyse the data collected into “categories based on themes, concepts or similar features” (Neuman, 2014:480). In this step, the researcher focused on identifying prominent themes, recurring ideas or language and patterns of belief that link the research participants together. This step is the most intellectually challenging phase of data analysis, as it requires a heightened awareness of the data and a focused attention to it (Schurink et al., 2016:410). Schurink et al. (2016:410) state that the mechanical reduction and analytical categorization of the data into themes help to cut the raw data into smaller more manageable piles. Breaking the data into a set of themes makes it easier to write the final narrative.

Coding may take several forms, including but not limited to abbreviations of key words, using colour code patterns such as coloured dots, cutting and pasting text segments onto sticky notes, or using computer software (Botma et al., 2016:225; Schurink et al., 2016:411). Although computer-based software would have made the coding process easier, the researcher found that she analysed and coded the data best by having her field notes and a hard copy of each transcribed interview in front of her. She made use of colour pencils and assorted colour sticky notes to code her data; allowing her to assign specific colours to emerging themes, concepts and similar emotions as communicated by the participants.

Step 6: Testing the emergent understandings and searching for alternative explanations

Schurink et al. (2011:415) assert that during the process of developing and coding categories and themes, the process of assessing, how things that are not in the data can be significant for analysis should commence. This involves searching through the data during which the researcher challenges the understanding, searches for negative instances of the patterns, and if necessary, incorporates these into larger constructs (Schurink et al., 2011:415). The researcher evaluated the data for its usefulness and centrality, and further determined whether the data contributes to finding answers to the questions asked in the study. Creswell (2009:183) mentions that the process of data analysis involves making sense of the text and image data. Co-coding of data was done and verified by the supervisor.

Step 7: Interpreting and developing typologies

The assumption exists that once the researcher has completed the process of data analysis, the answers are known, and the study is finalised; however, interpreting qualitative analysis is necessary before the study is deemed to be completed (Gray, 2017d:578). Therefore, a last step in data analysis involves the researcher interpreting or making sense of the data collected, i.e. determining “the lessons learned” (Botma et al., 2016:225; Schurink et al., 2016:416). Interpretation ultimately involves the researcher stepping back and asking the questions: “what do the findings mean?”; “what were the lessons learned?”; “were the objectives or research questions

addressed?"; "what do the findings mean for others?"; "should the study encourage change in some policies?"; and in the process forming broader opinions about what is happening in the data and the usefulness thereof (Botma et al., 2016:225; Brink et al., 2014:58; Grove et al., 2015:89; Schurink et al., 2016:416). Researchers often tend to hurry through the interpretation of the findings, but this process requires time for reflection and should not be minimized or hurried (Gray, 2017d:578). It is possible that if different researchers examine the text several valid interpretations may occur, however, it is essential that all interpretations remain trustworthy to the data and be data based, i.e. "grounded in the data" (Gray, 2017b:270). In qualitative research, the researcher often tries to construct a theory through the inductive process to describe relationships between categories of data; and, a theory that develops from data is referred to as "a grounded theory" (Thomas et al., 2011:368).

Two typologies can usually be distinguished. The first is linked to the emic approach, and the other is referred to as "first order interpretation" (Schurink et al., 2016:417). First-order classification requires that the researcher read between the lines of the data collected by establishing how the study participants see the world, how they define the situation, or what significance it holds for them (Schurink et al., 2016:417). In qualitative studies, first-order interpretation thus means that the researcher interprets the data collected by giving it meaning or making it understandable from the point of view of the study participants (Schurink et al., 2016:417). As the researcher aimed to explore and understand the personal experiences of adult children regarding a dementia diagnosis in their older parents, a first-order interpretation was most applicable. Analysing the data by using first-order interpretation, ensured that the researcher interpreted and understood the data not from her own perception, but through the eyes of the adult children who have parents living with AD.

Step 8: Presenting the data

In qualitative studies, the basic procedure for reporting the results of the study involves developing descriptions and themes from the data, presenting these themes, and ultimately conveying the multiple perspectives of research participants (Creswell, 2009:193). The phenomenological design allowed the researcher to truly submerge herself into and begin to understand what it must be like to have a parent living with

AD. As previously discussed, phenomenological studies aim to observe human experience through the accounts that are provided by the people involved (Brink et al., 2014:121), and it involves researchers asking themselves what it must be like to experience a specific phenomenon. By using a qualitative strategy of inquiry, the results may provide a detailed description of their experiences (Creswell, 2009:193). By adopting the qualitative approach and the phenomenological design, the researcher was able to present her findings in a way that communicates the emotions and difficulties faced by the group of adult children, but also the perspectives and personal experiences of each adult child individually. The researcher discusses and presents her data in the form of a research report, according to the guidelines of the Department of Social Work and Criminology, in which the background of the study, the contextualisation of the topic and the identified themes are discussed. Research results were substantiated with verbatim responses from participants and literature.

4.6.3 Trustworthiness

In qualitative research, the researcher's intention is to cultivate an understanding of the phenomenon by investigating the ways in which participants "experience, perceive, and make sense of their lives" (Kornbluh, 2015:397). In this study the researcher intended to shed light on the true extent of the rollercoaster ride faced by adult children whose parents were diagnosed with AD, and she attempted to describe this personal experience from the participants' perspective. Although each of the respondents were on the "AD rollercoaster", each of them experienced and perceived the ride in an individual and unique way.

While qualitative research has become more and more renowned and appreciated for its unique place in the field of social science, there is still a concern around assessing the quality of qualitative findings (Kornbluh, 2015:397). The term trustworthiness, or credibility, refers to the process of establishing whether a qualitative study is rigorous and of high quality; it is the degree to which a qualitative study is "dependable, confirmable, credible, and transferable" (Grove et al., 2015:392) and it refers to the degree of confidence in the data, clarification, and methods used to guarantee the quality of a study (Connelly, 2016:435). As mentioned above, trustworthiness is considered as the degree to which a study is dependable, confirmable, credible and

transferable, therefore, according to Rapport, Clement, Doel and Hutchings (2015:99) and Grove et al. (2015:392):

- Credibility can be assessed and assured if the researcher reports on the entire research process in detail; it is the assurance of the reader about the degree to which the researcher has produced results that reflect the views of the participants.
- Transferability refers to the perception that a study can become one example within a larger group; qualitative findings are not generalisable but are transferable or applicable in other settings with similar participants.
- Dependability proposes that the working processes supporting a study can be reported in enough detail for other researchers to positively extend knowledge and understanding.
- Confirmability is the “qualitative investigator's comparable concern to objectivity”, allowing findings to be visibly connected back to participant data rather than to the researcher's assumptions; and data can also be returned to participants for member checking.

Trustworthiness, or credibility, is recognised when findings as closely as possible mirror the meanings as described by the participants (Lincoln & Guba, 1985). Although it would have been impossible for the researcher to communicate exactly what each participant experienced, and continues to experience, in the face of an AD diagnoses of a parent, the researcher attempted to mirror as closely as possible the individual experiences and perceptions of each respondent. It is critical to recognize rigor in research; rigor refers to “quality or state of being very exact, careful, or with strict precision or the quality of being thorough and accurate” (Cypress, 2017:254). Rigor and truth are always of concern for qualitative research, and rigor has similarly been used to express features related to the qualitative research process; without rigor, research is insignificant, turns into fiction, and loses its usefulness (Cypress, 2017:254). Trustworthiness is one of the goals of the research study and, at the same time, it is something that needs to be judged during and after the research study is conducted (Cypress, 2017:255).

In his first publication, Guba (1981) referred to four trustworthiness concerns that all researchers need to address regardless of his/her research paradigm, these questions are:

1. How can a researcher establish confidence in his/her findings? Or how do we know if the findings presented are genuine? (Truth value concern)
2. How do we know or determine the applicability of the findings of the inquiry in other settings or with other participants? (Applicability concern)
3. How can one know if the findings would be repeated consistently with the similar (same) participants in the same context? (Consistency concern)
4. How do we know if the findings come solely from participants and the investigation was not influenced by the bias, motivations or interests of the researchers? (Neutrality concern).

Within qualitative research, the researcher is usually both the data collector and data analyst, which increases the possibility of researcher bias (Birt, Scott, Cavers, Campbell & Walter, 2016:1802). The rudimentary issue in relation to trustworthiness is simple: “How can an inquirer persuade his or her audience that the findings of an inquiry are worth paying attention to, worth taking account of?” (Lincoln & Guba, 1985:290). To ensure that trustworthiness is one of the main concerns of the researcher, Lincoln and Guba (1985), which is a seminal source and essential to the discussion of trustworthiness, provided criteria that has been accepted by many qualitative researchers to ensure the trustworthiness of a study, and an attempt to avoid personal bias impacting the research study. The researcher studied and applied the criteria outlined by Lincoln and Guba (1985) to report and reflect on the data collected, and to ensure that she communicated the personal experiences of each participant in a truthful and unbiased manner.

- **Reflexivity**

An essential element of trustworthiness is reflexivity. Reflexivity is “one of the pillars of ‘critical’ qualitative research and relates to the degree of influence that the researcher exerts, either intentionally or unintentionally, on the findings” (Jootun, McGhee & Marland, 2009:42). Reflexivity refers to the “responsibility of researchers to examine their influence in all aspects of qualitative inquiry – self-reflection” (Streubert, 2011b:34). It refers to the researcher’s process of reflective thinking during the

research study; this could involve the researcher writing memos or notes, or frequently using a journal to stay focused on the data (Cruz & Tantia, 2017:88; Cypress, 2017:259). During the process of reflexivity, researchers engage in critical self-reflection to identify and set aside any biases they might have; this process is referred to as bracketing (Cruz & Tantia, 2017:88; Gray, 2017a:65). Reflexivity and bracketing are processes that can assist researchers to always be on guard and sensitive of their own prejudices, expectations, views and presumptions which they might bring to the study (Cypress, 2017:258). Reflexivity means that one turns the researcher lens back onto oneself to identify and take accountability for one's own involvement within the research and the consequence that it may have on "the setting and people being studied, questions being asked, data being collected and its interpretation" (Berger, 2015:220).

To ensure the trustworthiness of her data, the researcher reflected on the information gathered from previous interviews and reminded herself that although the subject matter of the interviews was the same, the emotions and experiences of participants were not. The researcher had to remind herself not to expect the same answers or reflections from participants just because she anticipated that respondents would communicate similar experiences or perceptions. Reflexivity attempts to ensure that the knowledge produced during a research study is independent of the researcher producing it, and thus deems the information contained in the study as objective (Berger, 2015:220).

During the process of reflexivity, the researcher consciously and deliberately attempted to be attuned to her own reactions to participants and the way in which the research account is constructed. Thus, reflexivity aided in recognising and illuminating the probable or definite effect of individual, contextual, and circumstantial aspects on the process and conclusions of the study; and it further ensured that the researcher upheld her mindfulness of herself as part of the world she was studying (Berger, 2015:221). During the process of reflexivity, the researcher honestly assessed whether her personal background and history, perceptions and interests had any influence on the qualitative research process (Anney, 2014:8). Reflexivity in research increases transparency in the researcher's subjective role, "both in conducting research and analysing data, and allows the researcher to apply the necessary changes to ensure

the credibility of their findings” (Darawsheh, 2014:561). As previously discussed, it was important for the researcher to set aside her own memories, perceptions and experiences of an AD diagnoses of a family member to ensure that she had no personal bias or anticipations regarding the personal experiences of respondents.

Researchers should develop a tool, which will enable them to effectively maintain a self-reflective stance, once they are aware of the power their ideas may have on the level of understanding of the research findings (Streubert, 2011b:34). Interviews must be “interdependent by nature” (Streubert, 2011b:35) for it to be successful. For the researcher to access private and personal information, mutual respect and trust needs to be evident between the researcher and the informant (Streubert, 2011b:35). The researcher ensured that reflexive validity was a part of the entire research process, by continuously identifying and examining her own biases, suppositions and presuppositions regarding the phenomenon being studied (Streubert, 2011c:316). Being aware of her own perceptions and biases regarding an AD diagnosis and the impact that it has on a family member, the researcher was able to step back and tell the story of the participants from their view, and not her own.

- **Member checking**

Another aspect that goes hand in hand with reflexivity is the term “member checking”. Member checking occurs when the researcher returns to the informants/participants with the emerging findings and conclusions of study, to establish whether they recognise and agree with the findings as transcribed by the researcher (Brink et al., 2014:172; Streubert, 2011b:48; Thomas et al., 2011:36). Member checking “involves asking research participants to confirm or disconfirm the accuracy of the research observations and interpretations” (Rubin and Babbie; 2013:263). Therefore, member checking encompasses the researcher providing the participant with a copy of the interview or analysed data; which serves to “validate, verify, or assess the trustworthiness of qualitative results” (Birt et al., 2016:1802); or the researcher perusing the final report with each participant through conducting individual follow-up interviews (Botma et al., 2016:231).

As mentioned above, conducting follow-up interviews with each participant is a more interactive form of member checking, during which the transcription of the initial interview foregrounds the second interview; and during the second interview the researcher concentrates on confirming, modifying and verifying the interview transcript (Birt et al., 2016:1805). Additionally, the researcher may also make use of the individual participant's analysed data and the emerging findings as a basis for the member check interview (Birt et al., 2016:1805). Member checking can either be a distressing or therapeutic process for the participants, and as such each participant should be asked whether they wish to take part in any validation exercise, such as a follow-up interview (Birt et al., 2016:1806). Generally, member checking intends to increase the trustworthiness and, more precisely, the reliability of research; it also provides informants with increased opportunities to partake in the research process (Iivari, 2017:114). Through member checking, researchers can guarantee that their reconstructions are seen to be acceptable representations of the participants' realities (Iivari, 2017:114).

Conducting member checks has numerous advantages for both the researcher and the participant. They bid the opportunity to identify any personal biases which the researcher may have by soliciting alternate viewpoints concerning the interpretation of the data; they support the ethical responsibility of the researcher to guarantee the truthful presentation of participant accounts, and lived experiences; they provide the researcher with an opportunity to collect further facts, which addresses any gaps in information or areas of misperception; member checks provide the opportunity to cultivate a deeper understanding of the data, offering a variety of viewpoints; and member checks facilitate the engagement and understanding of participants with regards to the phenomenon, which can both update and increase their use of the findings (Kornbluh, 2015:399).

Although there are many advantages regarding member checks, disadvantages also exist. Participants may submit to the researcher as the professional, agreeing to the researcher's conclusions even if their perspectives differ; participants may question the researcher's intentions in truthfully presenting the findings, viewing the researcher as having personal biases influencing the analysis and disregarding the findings viewing their own perspective as irrelevant; participants may not comprehend the

findings, which can result in the researcher decontextualizing the findings into an one-dimensional form of analysis. Furthermore, participants may reject the analysis if conclusions conflict with their own personal interests and after imploring feedback from participants, the researcher has the difficult chore of including participant feedback into the conclusions of the study (Kornbluh, 2015:399-400).

Although the effectiveness of member checks, in establishing trustworthiness, has been debated (Kornbluh, 2015:411; Thomas, 2017:39), the researcher believed that conducting member check interviews would assist in establishing the trustworthiness of the study. Seeing that the participants of the study live in different towns in Namibia, it would have been both costly and time consuming for the researcher and therefore, the researcher made use of telephonic conversations and electronic mail to share the emerging findings and conclusions with the participants. Participants were asked to peruse the transcriptions of their individual interviews, the themes identified, and the conclusions drawn. If participants disagreed with any of the findings or conclusions, they were asked to inform the researcher either in writing or telephonically. This assisted the researcher in ensuring that the discussion of the data and the perceptions of the participants were done as truthfully as possible.

- **Peer debriefing**

A new set of eyes and ears can often shed new light on data collected and findings made by researchers; this is the essence of peer debriefing (Thomas et al., 2011:366; Brink et al., 2014:172). Peer debriefing means that researchers expose themselves to an unbiased colleague in a way that is like an investigative session, and for the purpose of exploring features of a study that might otherwise stay unspoken within the inquirer's mind (Lincoln & Guba, 1985:308). A peer debriefer is someone, who is not directly involved in the study, who scrutinises the data and conclusions made by the researcher; and this person ultimately plays the role of "devil's advocate" by questioning and challenging the researcher's findings to guarantee that it holds up (Brink et al., 2014:172; Thomas et al., 2011:366). Peer debriefers often have knowledge or a general understanding pertaining to the phenomenon being studied (Brink et al., 2014:172; Thomas et al., 2011:366), and as such they can provide informed critique and direction if necessary. Peer debriefing and support occurs when

groups of investigators meet frequently to provide each other with feedback, emotional support, and ideas, at which time they might exchange alternative viewpoints and fresh ideas with regards to how they are collecting data, about problems, and about meanings in the data they already collected (Rubin & Babbie, 2013:263). The aim of peer debriefing should not be for “independent analysts to attain the exact same coding and thematic structure as the researcher”, but instead the purpose should be to determine whether they agree with “the data labels and the logical paths taken to arrive at those labels” (Houghton, Casey, Shaw & Murphy, 2013:14). The idea behind peer debriefing is that the process increases the probability of identifying and correcting biases and other problems in data collection and interpretation (Rubin and Babbie, 2013:263). Lincoln and Guba (1985: 308) outlined multiple purposes of peer debriefing:

- From the point of credibility, the process of peer debriefing aids in keeping researchers “honest”, exposing them to probing questions by a knowledgeable peer, who is attempting to play the devil’s advocate. The researcher’s biases are explored, connotations probed, and the origin of interpretation illuminated.
- Debriefing provides a preliminary and probing opportunity to examine working hypotheses that may be developing in researchers’ minds. Hypotheses that may seem effortlessly sensible to an isolated researcher desperate for closure, may appear otherwise in the view of the impartial debriefer. If researchers cannot support the direction in which their minds are taking them, they may be asked to reconsider their positions.
- Peer debriefing provides the opportunity to develop and primarily assess the next steps in methodological design. It is the task of the debriefer to push the researcher on such steps, possibly even suggest some or question whether certain steps have been considered.
- Debriefing provides the researcher with an opportunity for release, thereby clearing the mind of emotions and feelings that may be blurring good judgment or inhibiting development of practical next steps (Lincoln & Guba, 1985:308).

The researcher worked closely with Mr. Berrie Holtzhausen who, although a participant in the research study, has a lot of knowledge and experience in the field of dementia, particularly in the Namibian context. As an expert in the field, he was able to provide

the researcher with insights and positive criticism, and he identified certain errors which the researcher overlooked.

- **Confirmability**

A final element of trustworthiness is that of confirmability, which is the “neutrality or the degree findings are consistent and could be repeated” (Connelley, 2016:435). Confirmability talks to the degree to which the outcomes of inquiry study could be established or substantiated by other researchers; it is “concerned with establishing that data and interpretations of the findings are not figments of the inquirer’s imagination but are clearly derived from the data” (Anney, 2014:279).

Research suggests that confirmability of a qualitative study is attained through “an audit trail, reflexive journal and triangulation” (Anney, 2014:279; Streubert, 2011b:49). Confirmability further refers to the degree to which other researchers can review the audit trail and agree that the authors’ conclusions are rational; when a study’s conclusions are judged to be “confirmable and dependable, they have credibility” (Grove et al., 2015:392). Confirmability is a “process of criterion”, and researchers document the confirmability of the findings by leaving an audit trail, which is “a recording of activities over time that another individual can follow” (Streubert, 2011b:49). The objective of an audit trail is to exemplify as clearly as possible, the facts and thought processes that led to the conclusions made by the researcher (Streubert, 2011b:49). Confirmability was met by the researcher maintaining a reflexive journal during the research process to jot down notes and document self-examinations on a daily basis, which was helpful and pertinent throughout the study and an audit trail which allowed for the examination of the processes whereby data was collected and analysed, and interpretations were made (Cypress, 2017:258).

The above aspects of trustworthiness, namely reflexivity, member checking, peer debriefing, and confirmability, challenged the researcher to examine her own perspectives and biases regarding the phenomenon; and this ensured that her interpretation of the data was a truthful reflection of what each participant truly believes and experienced.

4.7 ETHICAL CONSIDERATIONS

In research with human subjects, it is extremely important to adhere to ethical principles.

4.7.1 Avoidance of harm

Rubin and Babbie (2013:290) assert that social work research should never harm participants involved in the study. Harm is often caused to participants when information, which would embarrass them or endanger any aspect of their livelihood, is revealed (Rubin & Babbie, 2013:290). During a research study, participants can be harmed psychologically, and thus the researcher needs to ensure that all personal and intimate information about participants are treated with care and respect (Rubin & Babbie, 2013:290). Although physical injury cannot be ruled out, subjects in a social science research study are most often subjected to emotional harm (Strydom, 2011b:115) due to the personal questions that are used to obtain rich data about a particular phenomenon, often triggering emotional and painful flashbacks. Emotional harm to research participants is very often difficult to predict and determine, as opposed to physical harm, but it may have more far-reaching consequences for the participants (Strydom, 2011b:115). Strydom (2011b:115) states that as a result of the above mentioned, research participants should thus be thoroughly informed about the possible emotional discomfort that can appear during the research study.

This research study was interested in exploring and understanding the deep, personal experiences of adult children in relating to their parents who were diagnosed with dementia. The relationship between the parent and child often grows stronger as the child grows older, where the parent is not merely just a role model anymore, but also a confidant and friend. When dementia takes hold of a person's mind and body, they often lose the very essence of who they were. The researcher was aware that engaging in a conversation with the participants regarding the effect that such a diagnosis has had, and/or continues to have, on them and their relationship with their parents could trigger emotional and hurtful memories. For those who had an especially strong bond with the diagnosed parent, the questions could trigger lost memories and experiences, memories and moments, which the adult child may have stored away subconsciously.

Thus, the researcher informed the selected participants that the line of questioning may trigger certain emotions and memories, and if they did not think they would be able to handle it, they were welcome to withdraw from the study at any time, whether before or during the process. The researcher formulated the main question and probed participants in a manner that invited them to engage in a conversation, and not in a manner that made them feel they might be judged when responding. Should the researcher have picked up any form of emotional harm or distress, she would refer the participant to a counsellor identified in close vicinity to where the participant lives.

4.7.2 Debriefing participants

During debriefing, participants are provided with the opportunity to work through their experiences and ask questions or remove any misconceptions they might have after the study has been completed (Strydom, 2011b:122). Strydom (2011b:122) states that taking participants through a reflective and directed process enables them to discover things about themselves that they did not know. The researcher had debriefing sessions with each participant to allow him or her to ask questions or work through misconceptions that they might have had about the research study. These sessions might have helped the adult child come to terms with any decisions they made regarding the care of their parents, and it may also have helped shed some light on any uncertainties or misconceptions they have about the disease.

4.7.3 Voluntary participation

Social work research often signifies an intrusion into people's lives, as people are ever so often required to disclose personal information about themselves (Rubin & Babbie, 2013:287). A key principle of research ethics is that participation must be voluntary. Nobody was forced to partake in the study; all participants had to be aware that they were participating in the study; all participants were informed of all the consequences of the study; and all participants had to consent to participate in the study (Rubin & Babbie, 2013:288). In this research study, the researcher did not only explain the benefits that such a study holds, but she also mentioned that due to the topic of the study, emotional discomfort might occur. Each participant voluntarily took part in the

study and was not forced or manipulated into partaking. They could withdraw from the study at any time and without any negative consequences.

4.7.4 Informed consent

None of the participants were coerced to participate in the research study; it was essential that all participation was done voluntarily (Neuman, 2014:151). Informed consent is, according to Streubert and Carpenter (2011:61), a prerequisite for all research involving identifiable subjects. Carpenter (2011:61) states that informed consent means "... participants have adequate information regarding the research; are capable of comprehending the information; and have the power of free choice, enabling them to consent voluntarily to participate in the research or decline participation". This means that participants are asked to sign a consent form, which provides them with adequate information regarding the features of the study that might affect their decision about whether they want to participate or not (Rubin & Babbie, 2013:289). With this in mind, the researcher adequately informed research participants about the aim of the study, why the researcher believes it is a crucial topic to explore and what was expected of them as participants. The researcher explained that they were by no means forced to take part in the study, but that their contributions would help shed light on the lack of adequate health care facilities for the elderly in Namibia, as well as assist in identifying the impact of dementia on the relationship between the adult child and the parent.

Each research participant was asked to sign an informed consent form in which the aim, reason and possible emotional distresses were explained; and they agreed to voluntarily partake in the research study. By signing the informed consent form, however, participants were not forced to partake any further if they felt that the study was causing them any discomfort or unhappiness. They knew and consented to interviews being recorded for transcription purposes.

4.7.5 Deception of subjects

Deception is never preferable if one can achieve the same aim without deception (Neuman, 2014:151). Deception involves deliberately withholding information, or

offering the wrong information to participants, to ensure their participation in the study, especially when the truth or correct information may lead to subjects refusing to participate (Strydom, 2011a:230). Neuman (2014:151) asserts that deception is acceptable only if it has an explicit methodological purpose, and even then, it must be used only to the minimal degree necessary.

The researcher was aware that the topic that she discussed with the participants could trigger painful memories or emotional flashbacks. Thus, the researcher explained to each participant that the aim of the study was not to force him or her to linger on old memories or stir feelings of guilt regarding their relationship with their parents. Instead, the researcher wanted to shed new light on the challenges and difficult decisions adult children face when they are confronted with a diagnosis of AD in their parents. Participants were adequately informed that the findings of the research study may possibly be used to inform government of the lack of affordable frail care facilities in Namibia, and assist in the development and implementation of such facilities. The researcher further explained that participation was by no means mandatory, and that they were allowed to withdraw from the study at any time.

4.7.6 Violation of privacy, anonymity and confidentiality

Carpenter (2011:63) mentions that the “principle of beneficence, doing good and preventing harm, applies to providing confidentiality and anonymity for research participants”. Researchers, who conduct social research, need to take precautions to protect the privacy of the participants, as these researchers often transgress privacy of participants in order to study social behaviour (Neuman, 2014:154). Researchers, according to Neuman (2014:154), ensure privacy by not disclosing the identities of participants after the information has been gathered; and this takes two primary forms, namely anonymity and confidentiality.

Anonymity refers to “the ethical protection that participants remain nameless; their identity is protected from disclosure and remains unknown” (Neuman, 2014:155). Anonymity shelters the identity of specific persons from being known, whereas confidentiality means that researchers may ascribe names to information, but it is held in confidence or kept undisclosed from the public (Neuman, 2014:154). Carpenter

(2011:64) asserts that due to the nature of data collection in a qualitative investigation, anonymity is impossible, but even if one cannot assure anonymity, confidentiality should always be protected (Neuman, 2014:155). Researchers must ensure that they never make public the information collected in a way that links specific persons to it (Neuman, 2014:155). Confidentiality without anonymity occurs when researchers do not release individual data to the public, but privately link individual names to data on specific individuals.

The personal, one-to-one interaction between the researcher and the participant, during the interview process, allowed the researcher to know the participant in a personal way, which is not always possible in a quantitative study. The research assured that confidentiality was maintained at all times. To ensure that the privacy and confidentiality was not violated, the researcher embarked on the following:

- Only the researcher knew the identities and names of the research participants. Participants' names, identity numbers or other information, which could reveal their identities, were not published in the research manuscript. Participants were referred to by means of a numerical number.
- Each participant signed a consent form to allow the researcher to share only basic information with her field and research supervisors.
- The researcher did not use any hidden media devices, such as video cameras, microphones or one-way-mirrors. Each participant had to sign a consent form stating they allow the use of a digital recorder, which is visible at all times, during the one-on-one interviews.

4.7.7 Publication of findings

The research findings will be published in a research manuscript and a scientific publication, in which the researcher will analyse and discuss the data gathered. Verbatim examples will be used within the research manuscript as an indication of the research findings. The research manuscript and data collected will be stored in a safe at the University of Pretoria for 15 years.

4.8 CONCLUSION

In this chapter the researcher discussed the qualitative research approach as the approach most applicable for this study; applied research was looked at as the type of research most suited for this study as it helped the researcher attempted to address a specific concern and make recommendations to address the lack of services to cater for the needs of people living with AD and their family services; and the researcher approached and immersed herself in the experimenatal world of each respondent by making use of the phenomenological design. Furthermore, the researched made us of non-probability and purposive sampling to identify her study population and select the participants for the research study.

CHAPTER 5

EMPIRICAL RESEARCH

5.1. INTRODUCTION

The research question that this study aimed to answer is: What are the experiences of adult children, who made the decision to place their parents diagnosed with AD in the ADN Care Farm Namibia? Therefore, the goal of this study was to explore and describe the experiences of adult children, who made the decision to place their parents diagnosed with AD in a dementia care clinic in Namibia.

In this chapter the researcher presents the analysed researched data by discussing and classifying the findings under main and sub-themes identified during the data analysis phase.

5.2. EMPIRICAL FINDINGS

The researcher conducted in-depth interviews with eleven participants and interviews were recorded and transcribed. The names and identifying details of participants and their older parents were changed to ensure that confidentiality was maintained. An interactive qualitative approach, which refers to the interconnectedness of the different components of the research process, was used to explore the experiences of adult children in relation to their parents' AD diagnosis and to explore the availability of facilities and support services in Namibia for people living with AD. The researcher identified recurring themes through reading and re-reading the recorded data, organising participants' responses under the identified themes and by submitting the recorded and analysed data for peer review. The researcher further recorded the biographical data of participants and their older parents in a table format, and the biographical data of staff and residents at the ADN Care Farm was also recorded in table format.

5.2.1 Biographical data of participants

In this study, the researcher conducted individual interviews with adult children who each had a parent living with AD. Although all participants had exposure to AD each of them comes from different backgrounds, differ in ages and their parents have not been in the same care facility for the same number of years. In the table below the biographical data of each participant and their parent are presented.

TABLE 2: BIOGRAPHICAL DATA OF ADULT CHILDREN AND OLDER PARENTS

Participant	Biographical category	
1	Gender	Female
	Age	55
	Parent	Mother
	Gender	Female
	Age	76
	Number of years that parent has been in the care of ADN	2
2	Gender	Female
	Age	63
	Parent	Mother
	Gender	Female
	Age	90
	Number of years that parent has been in the care of ADN	7
3	Gender	Male
	Age	37
	Parent	Father
	Gender	Male
	Age	78
	Number of years that parent has been in the care of ADN	3
4	Gender	Female
	Age	44
	Parent	Father
	Gender	Male
	Age	69
	Number of years that parent has been in the care of ADN	2.5
5	Gender	Female
	Age	35
	Parent	Mother
	Gender	Female
	Age	72

	Number of years that parent has been in the care of ADN	3
6	Gender	Male
	Age	38
	Parent	Father
	Gender	Male
	Age	69
	Number of years that parent has been in the care of ADN	2.5
7	Gender	Female
	Age	42
	Parent	Father
	Gender	Male
	Age	78
	Number of years that parent has been in the care of ADN	3
8	Gender	Female
	Age	52
	Parent	Mother
	Gender	Female
	Age	86
	Number of years that parent has been in the care of ADN	8
9	Gender	Female
	Age	39
	Parent	Mother
	Gender	Female
	Age	77
	Number of years that parent has been in the care of ADN	5 - 6
10	Gender	Female
	Age	39
	Parent	Mother
	Gender	Female
	Age	76
	Number of years that parent has been in the care of ADN	2

To gain more insight into dementia in Namibia the researcher conducted a one on one interview with Mr. Berrie Holtzhausen who is the founder of ADN. Mr. Holtzhausen is passionate and knowledgeable about dementia and as such he was a primary source of information in this study.

TABLE 3: BIOGRAPHICAL DATA OF THE ADN CARE FARM

Participant	Biographical category	
11	Gender	Male
	Age	63
	Establishment of ADN	January 2011
	Number of staff members	15 (Female) 2 (Male)
	Number of Residents	20

5.2.2 Thematic analysis of participants' experiences

The researcher extensively analysed the recorded and transcribed interviews through reading and identifying recurring themes. Once the themes were identified the researcher color coded the identified responses and research findings were classified under each theme. The table below provides an overview of the identified themes and sub-themes. In the discussion that will follow the researcher will discuss the research findings under each identified theme.

TABLE 4: SUMMARY OF THEMES AND SUBTHEMES

Emotions accompanying AD diagnosis	Main theme 1: The adult children of the older parent diagnosed with AD experience numerous emotions	Sub theme 1.1: Initial emotions of participants after the AD diagnosis of their parent Sub theme 1.2: Continuous emotions experienced Sub theme 1.3: Emotions in retrospect
Older parent placed in ADN Care Farm	Main theme 2: Placement of older parent in ADN Care Farm	Sub theme 2.1: Slow progression of disease Sub theme 2.2: Physical and financial wellbeing of parent

		<p>Sub theme 2.3: Caregiver burnout</p> <p>Sub theme 2.4: Adult child has no support</p>
Care facilities for people living with AD in Namibia	Main theme 3: There is a lack of facilities specialising in Alzheimer's care in Namibia	<p>Sub theme 3.1: Participants struggled to find specialised care</p> <p>Sub theme 3.2: Not all homes for the aged can care for Alzheimer's patients</p>
People living with AD require specialised care	Main theme 4: The ADN Care Farm provides specialised care	<p>Sub theme 4.1: ADN Care Farm caters for the physical needs of residents</p> <p>Sub theme 4.2: ADN Care Farm allows adult children to live their lives without worrying about their parents' wellbeing</p>
Support received when older parent was placed in ADN Care Farm	<p>Main theme 5.1: Participants received support for their decision</p> <p>Main theme 5.2: Participants experienced lack of support through criticism</p>	<p>Sub theme 5.2.1: Participants experienced that AD and the care centre carries a stigma</p> <p>Sub theme 5.2.2: Participants are criticised for their decision</p>
Impact of Alzheimer's disease on relationships	Main theme 6: Alzheimer's disease has an influence on relationships	<p>Sub theme 6.1: The AD diagnosis has an impact on sibling relationships</p> <p>Sub theme 6.2: AD impacts the relationship between the adult child and older adult</p>

		<p>Sub theme 6.3: Adult children experience an immense sense of loss</p> <p>Sub theme 6.4: Adult children grieve the changes that AD brought about in their parents</p> <p>Sub theme 6.5: The AD diagnosis has an influence on all the systems of the adult child</p>
Role reversal	Main theme 7: When parents grow older the adult child's role changes	<p>Sub theme 7.1: The adult child attempts to fill the void left by the parent</p> <p>Sub theme 7.2: The adult child becomes the parent to their parent with Alzheimer's</p> <p>Sub theme 7.3: Adult children experience numerous emotions related to the role reversal</p>
Awareness raising and education	Main theme 8: There is a need for awareness raising and education about AD in Namibia	<p>Sub-theme 8.1: No information was made available to participants and they needed to educate themselves on AD</p> <p>Sub-theme 8.2: There is a need for awareness raising in Africa where different cultures have different beliefs</p>

		Sub-theme 8.3: Medical practitioners and care givers are not educated or trained
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5.2.2.1. Emotions accompanying an AD diagnosis

Receiving an AD diagnosis is never easy, and the news that one’s parent has a terminal disease is often met with a variety of emotions.

5.2.2.1.1. Main theme 1: The adult children of the older parent diagnosed with AD experience numerous emotions

Dementia is not experienced by individuals in isolation (Holdsworth & McCabe, 2018:4). AD is one of the most frequent causes of dependence in the aging population and the effects thereof extend beyond the individuals to their primary caregiver and every person in their family and social systems (Pérez-Fuentes, Linares, Fernández & Jurado, 2016:56; Tuscan Gardens, 2016). As a loved one slowly deteriorates, family members must learn to cope with new duties and responsibilities, changes in the family system and their changing emotional responses to their loved one’s disease (Tuscan Gardens, 2016). Witnessing dementia in a parent is one of the hardest things that an adult child needs to face, and seeing their former caretakers deteriorate and become more and more dependent and disabled is devastating (Greenberg, 2017). Even in the early stages of the disease one comes face to face with the vulnerability of someone who was once strong and dependable, and the emotional implications can appear to be endless and overwhelming (Greenberg, 2017).

- **Sub theme 1.1: Initial emotions of participants after the AD diagnosis of their parent**

Receiving a diagnosis of AD is not easy, and very often families realise that they are unprepared to face the complex emotions and difficulties that accompany a dementia diagnosis (Gerontological Society of America, 2018:58). Once an older parent has been diagnosed with AD the adult children often experience a tremendous sense of “powerlessness, abandonment, and loneliness but also anger against the demented

parent at how they changed” (Kjällman-Alm, Norbergh & Hellzen, 2013:4). Kjällman-Alm et al. (2013:4) further state adult children frequently experience a sense of fear of inheriting the disease, they long for what has been, and they miss how they were able to communicate with their older parent before AD. All participants stated that they experienced some type of emotion once the doctor informed them that their older parent has AD. Although participants reported different emotions and degrees to which emotions were experienced, there were similar emotions experienced by the adult children. To determine the impact that the AD diagnosis had on the adult child, the researcher asked participants what their initial emotions were after they received the diagnosis.

The emotions mentioned by the participants were negative. Three participants mentioned that they experienced both shock and a sense of fear about what lies ahead when they were informed that their parent was living with AD.

Participant 1: *“Skok, ons was baie geskok gewees, en dan sit jy mos nou ook half met daai vrees, dis ‘n oorerflike ding, jy wil amper nie vra, who is next nie?”* [“Shock, we were very shocked, and one also sits with that fear, it is something that can be inherited, you almost do not want to ask, who’s next?”]

Participant 6: *“Dit was bietjie skok en bietjie bang en hoe gaan dit in die toekomst lyk?”* [“It was a bit of shock and fear and how is it going to look in future?”]

Participant 10: *“Toe ons besef my Ma het Alzheimer’s toe onthou ek my oupa, haar Pa het presies dit gedoen wat sy gedoen het, wat beteken oupa het ook Alzheimer’s gehad, en wat sê dit vir my? Dis in onse bloedlyn en dis wat vir my scary maak, ek raak sommer heel wild as ek nie ‘n ding kan onthou nie.”* [When we realised that my mother has Alzheimer’s I remembered that my grandfather, her father did exactly what she did, which means that my grandfather also had Alzheimer’s, and what does that tell me? It is in our bloodline and that is scary, I become crazy when if I can’t remember something.”]

Participant 2 noted that when they initially received the diagnosis, it was not easy, and she faced an array of emotions. Although her initial emotion was that of disbelief, she also experienced a mix of additional emotions.

“Aan die begin is dit nie maklik nie want jy gaan deur verskillende emosies, jy’s kwaad, eers skaam dan raak jy kwaad. Skaam omdat mense stigma daaraan het en dan raak jy kwaad. Hoekom? Maar jy weet eintlik nie hoekom jy kwaad is nie, maar jy is kwaad dis al wat saak maak. En dan op ‘n dag, dan besef jy, ‘Ag, daar’s baie mense wat baie erger as jy in die lewe het’. Ja, partykeer jy is in ongeloof, jy glo dit nie. In my opinie, ek het dit, wat kan jy sê in Afrikaans, ek het dit deny, ‘Ag, dis nie waar nie’, want ek het weggekrui agter die feit dat sy nie getoets was nie. En dan was ek op ‘n tydjie skaam gewees omdat my Ma so is. Ek dink dit kom deur familie wat gesê het, “Maar dis nie in ons familie nie’. Dan dink ek, ‘Okay, maar ons is familie en dis nou in ons familie, toe kom ek op ‘n tyd wat ek dit begin aanvaar het.’” [“At the beginning it is not easy, because you go through various emotions, you’re angry, first you are ashamed then you become angry. Ashamed because people attach a stigma to it and then you become angry. Why? But you do not actually know why you are angry, but you know you are angry and that’s all that matters. And then one day you suddenly realise, ‘Ag, there are many people who are worse of then you’. Yes, sometimes you are in disbelief, you do not believe it and then you start to. In my opinion, I denied it, “Ag, it is not true” because I was hiding behind the fact that, she wasn’t tested. And then there was a time when I was ashamed because my mother was like that. I think it came from the family that said, “But that’s not in our family”. Then I think, “Okay, but we are family and it is in our family now” then I came to a point where I started to accept it.”]

Like the above mentioned participant, Participant 4 explained that although she was saddened by the news, she was also shocked as no one in her family had ever been diagnosed with AD. Participant 8 similarly added that when they received the diagnosis they did not realise what it entailed and that when one has never had someone in the family diagnosed with AD one does not think about the disease.

Participant 4: *“Hartseer want dis jou Pa. Ek was hartseer, ons het almal natuurlik ‘n bietjie gehuil. Ja, so ons was, ons was in die eenkant was on half geskok gewees want ons het nog niemand in die familie gehad wat Alzheimer’s het nie.”* [“Sad, because it is your father you know. I was sad, obviously we all cried a little bit. Yes, so we were, on the one hand we were kind of shocked because we have never had anyone in the family with Alzheimer’s.”]

Participant 8: *“Ek weet nie, ek dink nie ek het besef nie. Ek het nie besef wat vir ons voorlê.”* [“I do not know; I do not think I realised it. I didn’t realise what lay ahead for us.”]

A common emotion that has emerged between participants is that of unbelief, and two participants explained that when learning that a parent is sick one does not really know what it means or what it entails.

Participant 5: *“Daai oomblik besef jy nie rêrig what’s going on nie. Dit het obviously, jy besef dit het impak en jy besef weet ons praat met ‘n terminale siekte, terminal siekte het nie vir jou, dit kom nie in jou kop tot, tot later nie.”* [“At that moment you do not really know what’s going on. It obviously has, you realise it has an impact and you realise, you know, we are talking about a terminal illness, terminal illness does not, it does not come to your mind until later.”]

Participant 8: *“Ja, en ek het nie besef wat dit is nie, genuine. Ek het nie eers gaan lees daai tyd daaroor nie, wat ek moes gedoen het.”* [“Yes, and I didn’t realise what it was, genuine. I didn’t even go read about that time, which I should have done.”]

One participant indicated that the diagnosis did not come as a shock, because their father was showing signs of AD long before they received the diagnosis. However, he stated that it was not comforting when the doctor confirmed their suspicions, but they had to come to a point where they accepted that their father is living with AD.

Participant 3: *“Kyk, dis nie lekker nie, dis nie lekker nie. My Ma het dit nie baie goed gevat nie, maar nou ja, ons het geweet dit is wat dit is.”* [“Look, it is not nice, it is not nice. My mother didn’t take it very well, but yes, we knew it is what it is.”]

Participant 6 stated that although AD was not something that they expected it was something they had to come to terms with, because there is nothing that one can do about it. He further mentioned that before his father was diagnosed with AD, he never knew anything about AD and he only started educating himself after they received the diagnosis.

“Jy kan niks daaraan doen nie, so dit is maar net ‘n, dit is nou iets wat begin hierso. Maar ek het nog nooit daai tyd, stadium het ek nog my gesteur aan Alzheimer’s nie of bietjie navorsing daaroor gedoen nie. Ek het begin meer die navorsing doen.” [“You can do nothing about it, so it is just, it is something that’s starting here. But at that time, stage I was never bothered with Alzheimer’s and never did a little research. Uhm, I started doing more research.”]

Another emotion that seemed to accompany fear and sadness was that of uncertainty. Participant 7 stated that although she was very disheartened when the doctor informed them of the diagnosis, she also felt a sense of uncertainty about what lie ahead.

“Ag, dit was maar baie hartseer, onsekerheid oor wat gaan kom. Dit het mens ook in ‘n mate bietjie bang gemaak want jy weet nie wat om te verwag nie. Die hele idee dat hy sy geheue gaan verloor en heeltemal die jy weet, die familie nie meer gaan herken nie, dis was ook nogal vir my ook nogal ‘n skok.” [“Ag, it is very sad. Uncertainty about what, what is going to come. It also scared me to a certain extent because you do not know what to expect. The whole idea that he is going to lose his memory and you know that he will completely forget the entire family, that was actually also a, also because you know it was a shock.”]

Although an AD disease diagnosis is something no child wishes for their parents, Participant 8 and Participant 9 stated that they were not angry when they received the diagnosis. Furthermore, the husband of Participant 9 stated that he does not remember

his wife (Participant 9) ever being angry because of the AD diagnosis, but he remembers that she did feel sorry for her mother and that she was sad about the diagnosis.

Participant 8: *“Hartseer, ja. Baie meer hartseer as kwaad.”* [“Sad, yes. Much more sad than angry.”]

Participant 9: *“Ja, ek wil nie hê my Ma moet dit deur gaan nie. Kyk, dood is iets waarmee ek groot geword he en siektes, ek gaan nie kwaad raak vir so iets nie want jy kan niks daaromtrent doen nie. Ek sal graag die persoon wil gelukkig hou, dit was my mission met my Ma gewees heeltyd is net om haar te probeer gelukkig hou want dis al wat ek doen.”* [“Yes, I do not want my mother to go through that. Look, death is something I grew up with and illnesses, I am not going to be angry because you can do nothing about it. I would want to keep the person happy, that was my mission with my mother the whole time, to just try and keep her happy because that is all I wanted to do.”]

Husband (Participant 9): *“Nee, jy het nie kwaad in jou gehad oor die siekte nie. Jammerte, hartseer ja, maar nie kwaad nie.”* [“No, you didn’t have anger in you because of the illness.”]

Participant 9 mentioned that once they received the news that her mother has AD, she had no clue what it meant, because to her Alzheimer’s meant that a person was merely forgetful.

“Nie ‘n clue nie, want ek het geken Alzheimer’s beteken mense is vergeetagtig, ek het niks van die res geweet nie. So dit het, jy weet, ‘Ja, sy word oud en sy vergeet, dit is nie vir my so erg nie’ totdat ons regtig begin uitvind het waaroor dit actually gaan.” [“Not a clue, because I knew Alzheimer’s means that people are forgetful, I knew nothing about the rest. So, it, you know, ‘Yes, she is getting older and she forgets, it is not that bad’ until we really started finding out what it is really about.”]

Mr. Berrie Holtzhausen is the head of ADN and as such he has regular contact with the adult children of parents living with AD. The researcher deemed it essential to ask him about his perceptions regarding the emotions that accompany an AD diagnosis.

“Wel ek dink, ek dink die eerste emosies dink ek, ek weet nie r rig nie maar ek dink ek is, is van hopeloosheid. Jy weet dit is soos kanker s  40 jaar terug was, die groot ‘K’ by baie mense vandag nog, maar baie kanker is geneesbaar. Byvoorbeeld laas jaar het ‘n tannie in Gobabis haarself doodgeskiet nadat sy die diagnose gekry het en die dokter het nie vir haar ges  na die diagnose, ‘Luister hier mevrou, gaan hier na hierdie plek toe laat hulle vir jou verduidelik wat is die trajek nou, wat is die proses nou voorentoe’ en dan vir haar hoop gegee het voor hy haar uitgestuur het, vir haar ges  het, ‘Onthou dit is nie, dit is nie jou doodsvonnis nie. Jy kan nog kwaliteit lewe h  vir baie jare, maar daar is goed wat julle in plek sal moet kry’. So ek dink dit is die eerste emosie wat mense kry, dis oor en uit en verby.” [Well I think, I think that the first emotions I think, I do not really know but I think it is, is a feeling of total hopelessness. You know it was like cancer was 40 years ago, the big ‘C’ with many people still today, but cancer is curable. For example last year a lady in Gobabis fatally shot herself after she received the diagnosis and the doctor didn’t tell her after the diagnosis, ‘Listen here madam, go to this place so that they can explain the trajectory that is to follow, what the process is going forward’ and then giving her hope before sending her away, saying ‘Remember it is not, it is not your death sentence. You can still have quality of life for many more years, but there are things that you will need to get in place’. So, I think those are the first emotions that people get that it is over and out.”]

Grief is a normal multifaceted psychological and emotional reaction which occurs as a response to significant loss (Chan, Livingston, Jones & Sampson, 2012:1). According to the Alzheimer’s Society of Canada (2018b) one can think of the reaction to hearing bad news as having five phases. Each of these phases are experienced in different ways and to different degrees by everyone, and there are no time limits to the range of reactions and emotions that people go through once they receive the news that their parent/s are living with AD (Alzheimer’s Society Canada, 2018b). These five phases

correlate with the five stages of grief, namely: denial, anger, bargaining, depression and acceptance (Spiess, McLemore, Zinyemba, Ortiz & Meyr, 2014:736):

1. Shock and numbness: Even if the adult children were aware of their parent's changing behaviour and deterioration, a diagnosis of dementia can come as a shock.
2. Disbelief and denial: Initially denial can be a positive emotion as one uses denial to shield yourself from news that is too painful to bear, and it allows you to adjust inwardly to your new reality;
3. "A 'hurricane' or a 'roller-coaster ride' of uncomfortable feelings of anger and frustration; a trajectory through emotional devastation": The reactions and emotions, such as frustration and anger, experienced after receiving the diagnosis does not disappear immediately and takes time to sort through. However, it has been found that some individuals experience a sense of relief to know once they know that there is a medical reason behind the changes they have noticed in their parent's behaviour;
4. Despondency and sadness: All adult children will go through stages where they feel helpless and powerless when they come face to face with the true implications of AD;
5. Acceptance: Eventually most individuals reach a stage where they accept the problem rather than avoid it, and they come to the realization that the situation they find themselves in cannot be changed but should instead be adjusted to (Alzheimer's Society Canada, 2018b).

Similarly to the above, it is believed that grief occurs in five stages and these stages mirror the above reaction to hearing bad news. Firstly, denial is the "conscious or unconscious decision to refuse to admit that something is wrong" (Spiess et al., 2014:736). When confronted with a dementia diagnosis in a parent, denial is one of the emotional responses that often initially occur; a way to consciously or subconsciously protect oneself against the reality of the dementia diagnosis. Secondly, anger is "an emotional or physical act in which the patient attempts to place blame" (Spiess et al., 2014:736) on someone or something else. A dementia diagnosis can derail one's life and relationships, and anger is one of the most common responses to a dementia diagnosis. Thirdly, bargaining is referred to as a negotiative process in

which individuals try to delay or distance themselves from the reality of a situation (Spiess et al., 2014:736) such as a dementia diagnosis. An adult child who has just found out that their parent has dementia sometimes distance themselves from their parent or the disease to escape the grim reality of the disease. The subconscious belief exists that if they do not confront the disease then it will not be a reality. Fourthly, depression is the “feeling of loss of control or hopelessness with a situation” (Spiess et al., 2014:736). Knowing that dementia is ultimately a fatal disease can leave the adult child with a feeling of immense sadness and loss as they begin to confront the reality that they will lose their parent sooner than expected and they have no power to change it. Finally, acceptance occurs when the adult child acknowledges and accepts that their parent is living with dementia and that no cure exists. The adult child realises that their parent will lose their memory, their physical ability will be negatively impacted and that there is nothing they can do but love and support their parent until they pass away.

- **Sub theme 1.2: Continuous emotions experienced**

Two participants stated that they were in a state of shock and disbelief for a long time after their parents were diagnosed.

Participant 1: *“Daar is net somtyds wat ek, wat ek gaan vra, ‘Here, hoekom, hoekom Mamma?’ wat so betrokke was in die kerk en in die gemeente en in die gemeenskap.”* [“There are times when I ask, when I go ask “Lord, why, why my mother?” who was so involved in church and in the community.”]

Participant 2: *“Ek was eintlik geskok gewees, maar ek het dit nie geglo nie, dit kan nie wees nie. Ek het altyd gedink, ag dis tipies ou mense vergeet mos maar net, en sy het verskillende stadiums gekry wat ek haar dopgehou het en ek het gedink, ‘Nee man, dit moet Alzheimer’s wees’.”* [“I was actually just shocked, but I didn’t believe it, I really didn’t believe it, it could not be, but I always thought, ag it is typical, old people are prone to forgetting, and she reached different phases where I would sit and watch her and I would think, “No man, it has to be Alzheimer’s disease.”]

One participant stated that although they have been walking this road with her mother for many years, she only recently came to accept that her mother really is ill and that she would not be getting better and that it is something she had to figure out as she went along.

Participant 5: *“En ons stap nou al ses jaar lank die paadjie en hierdie week het dit vir die die eerste keer r rig begin inset by my dat my mamma is r rig siek, Weet, dit gaan nou baie sleg met haar, nie fisies gewys nie. Iemand wat haar, wat nie besef waaroor dit gaan nie gaan na haar kyk en gaan, ’Sy’s net’n ou dame’, maar wat in haar liggaam besig is om aan te gaan, biologies is daai is erg en ek sal s  dis net verslae. Dit was vir my alles baie nuut gewees.”* [“And we have been walking this road for six years and it only began to settle that my mother is really sick. You know, she’s not doing very well right now, not physically speaking. Someone that does not realize what it is about will look at her and say, “She’s just an old lady”, but what is busy happening in her body, biologically that is tough, and I’ll say it is just astonishment. It was just new to me.”]

Participant 5: *“Die trane kom later. Dis nie soos ’n motorongeluk of iets nie, dis ’n hele proses waardeur mens gaan, en glo my, dis maar moeilik, ek meen jy weet, jy weet dit kom maar you kind of figure it out.”* [“The tears come later. It is not like a vehicle accident, it is a whole process that you go through, and believe me it is difficult, I mean you know, you know it comes but you kind of figure it out.”]

Participant 6 stated that although he is not angry that his father has AD, it is upsetting to see his father battle this disease: *“Ja, dat dit met hom gebeur het, dis maar ’n hartseer storie, en dit is my Pa. Dis maar treurig wat met hom gebeur het.”* [“Yes, that it happened to him, it is a sad story, and it is my dad. It is sad what happened to him.”]

- **Sub-theme 1.3: Emotions in retrospect**

Dementia is a common phenomenon that more and more people are coming face to face with. Although it is a journey familiar to many, the dementia experience is unique and personal to everyone. Adult children often face feelings of regret about things they could or should have done differently, and some feel like they abandoned their parents

the day they placed them in a care facility. A prevalent idea of why one has obligations towards one's elderly parents is that of reciprocity: "adult children owe something to their elderly parents because their parents have done much for them" (Stuifbergen & Van Delden, 2011:64). More than one participant stated that one of the most difficult aspects of their parents' diagnosis is the fact that they can do nothing for their parents except ensure that they are well taken care of.

Participant 5: *"En die feit dat jou ouer vir jou hulle hele lewe lank alles gegee het wat hulle kan en ek kan nie die favour repay nie. Wel ek doen alles wat ek kan, maar jy kan nie, you can't make it better. Daai hulpeloosheid dis crap."* ["And the fact that for your entire life your parents gave you everything they could, and you can do nothing to repay the favour. Well, I am doing everything I can, but you can't, you can't make it better. That helplessness is crap."]

Participant 6: *"Wat ek graag wil hê, en dit klink nou baie lelik en so, dat my Pa net sy oë toemaak want ek wil hom nie so sien ly nie. Jy weet, ek hou nie daarvan nie. Ek, ek hou nie van daai, om hom so te sien nie. Dit, dit breek rêrig my hart en dit maak my rêrig seer om hom so te sien."* ["What I really want, and it is going to sound very mean, that my father will just close his eyes because I do not want to see him suffer. You know, I do not like it. I do not like that, to see him like that. It, it, it really breaks my heart and it really hurts me to see him like that."]

Participant 7: *"Daai agteruitgaan van, van sy hele menswees. Dit is soos 'n persoon wat voor jou vernietig word en jy kan niks daaraan doen nie. Dit is, dit is vir my die ergste."* ["That deterioration of, of his entire entire being. It is like a person being destroyed in front of you and you can do nothing about it. For me that is the worst."]

Participant 9: *"Om nie rêrig vir hulle te kan verduidelik wat gebeur met hulle nie. Ek is seker mens kan vir hulle verduidelik, maar ek weet nie of hulle dit verstaan en begryp nie. Om vir hulle te sien hulpeloos voel en jy kan nie vir hulle dit laat sense maak nie van wat gebeur nou nie."* [To not really be able to explain what is happening to them. I am sure one can explain it to them, but I do not know if they

understand it or grasp it. To see them feel helpless and you can't make it make sense to them.”]

Participant 10: *“Wat vir my die moeilikste was is die feit dat sy het letterlik onder onse oë weggekwyn en daar is niks wat jy kan doen nie, absoluut niks. Jy kan nie ‘n pil gee om dit beter te maak nie of jy kan nie die leefwyse verander om dit beter te maak nie, maar jy besef net bietjie vir bietjie dat sy is besig om agteruit te gaan.”* [What was the most difficult for me is the fact that she was literally deteriorating in front of our eyes and there is nothing you can do about it, absolutely nothing. You can't give a pill to make it better or you can't change the lifestyle to make it better, but you just realise bit for bit that she is busy deteriorating.”]

When asked if she was every angry because of her father's diagnosis, Participant 7 indicated that her father living with AD did anger her because she could not understand why and how it happened to him.

“Ek was op ‘n stadium ja, want ek kon nie verstaan hoekom gebeur dit met hom nie, want hy was ‘n baie goeie mens. Hy was ‘n moeilike mens, maar hy het, hy het ‘n verskriklike goeie hart gehad en hy het so baie mense gehelp. Ek kan nie verstaan nie, hoekom moet dit met hom gebeur? Ek was op ‘n stadium kwaad ja, definitief. Ek kon nie verstaan hoekom gebeur dit met hom nie.” [“At a stage I was yes, because I could not understand why it is happening to him, because he was a very good person. He was a difficult person, but he had, he had a very good heart and he helped so many people. I can't understand that, why did it happen to him? I was angry at one point, definitely. I could not understand why it was happening to him.”]

Participant 10 stated that although she was never angry that her mother must live with AD, she was angry at and disappointed in herself for not forcing her mother to see a councillor after her father's death. *“Ek was kwaad vir myself en teleurgesteld in myself omdat ek nie genoeg force op Mamma gesit het sodat sy kon gegaan het vir terapie na Pappa se dood, want ek het op daai stadium gebesef dat sou sy met iemand kon gesels het en ‘n padjie met iemand geloop het en daar het werklik haar emosies deurgewerk het met ‘n councillor dan.”* [“I was angry at myself and disappointed in

myself because I did not put enough force on my mother so that she would go for therapy after my father's death, because I realised at that moment that if she was to speak to someone and walked a road with someone and really worked through her emotions with a councillor.”]

Participant 10 further mentioned that one of the most difficult things she had to do was come to terms with her mother's diagnosis, as she had to accept the fact that her mother was not the same person she used to be and that their relationship has forever been changed by AD.

“So ek het die laaste vier, vyf maande het ek ‘n baie diep padjie met die Here geloop as gevolg van die diagnose want ek moes vrede vind in die omstandighede. Ek moes vir myself sê dat, ‘Dis jou Ma. Dit is nie haar skuld dat sy daar sit nie. Dis nie haar skuld dat sy nie meer met jou kan terug praat nie’. Sy’s nie siek nie, maar sy kan nie meer met jou kommunikeer soos wat dit was nie. Ek moet vir myself sê sy is nie ‘n gestremde nie, ek moet vir myself sê, ‘Mamma word net geversorg’ en, en wat vir my baie moeilik is, is die feit dat soos nou in hierdie laaste tye, sy ken ons mos glad nie.” [“So, for the last four, five months I walked a serious path with God as a result because of this because I had to find peace in the circumstances. I had to tell myself that, ‘It is your mother. It is not her fault that she is there. It is not her fault that she can’t talk back to you anymore’. She’s not really sick, but she can’t communicate with you anymore like she used to. I need to tell myself that she is not disabled, I need to tell myself, ‘Mom is only being cared for’ and, and what is difficult for me is, is the fact that recently, she does not know us at all”]

Although most emotions connected to an AD is negative, some participants reported positive emotions in hindsight.

Participant 5: *“Op daai stadium wat my Ma gediagnoseer is was ek baie verlig dat daar wel ‘n diagnose was vir dit waarmee ons gesit het. So, toe ek uiteindelik ‘n diagnose by dit was fout is kry, was ek so half verlig daarvoor want ek het half, ek kon asem haal.”* [“At the point that my mother was diagnosed I was very relieved that there was indeed a diagnosis for that which we had been faced with. So, when

I finally received a diagnosis, I was kind of relieved about it because I could kind of, I could breathe.”]

Participant 10: *“So, dit was ‘n verskriklike, dit was ‘n verskriklike emosionele stryd die laaste gedeelte van die jaar, maar ek dink ek het vrede gevind in die omstandighede.”* [“So, it was an extremely, it was an extremely emotional battle the last part of the year, but I think I have found peace in the circumstances”]

Although not all older parents with dementia will need to be moved to a nursing home or care facility as many do, the transition to a care facility is one of the most difficult transitions for everyone involved (Alzheimer’s Society of Ireland and the Irish Hospice Foundation, 2015:3). Adult children grieve another change in their relationship with their parent; feelings of loss and grief are mixed up with guilt and relief, and these emotions can last for a long time (Alzheimer’s Society of Ireland and the Irish Hospice Foundation, 2015:3). One of the most prominent emotions experienced by participants is guilt for placing their parent in the care of the ADN Care Farm because it felt like they were abandoning their older parent. Very often family members experience an immense sense of guilt for placing their older parent in a care facility, because they feel like they should have kept them home for longer even though they know that they would not be able to provide the specialised care their parents need (Alzheimer’s Society of Canada, 2017).

Participant 1: *“En toe het hierdie sussie van my, die tweede week toe het sy net vir my gesê, ‘Ek gaan afsprake maak met mense, ek gaan vir Mamma ‘n versorgingsplek soek’ en dit was vir my ‘n vuishou gewees, want dit voel so vir jou jy gooi jou mens weg.”* [“And then this sister of mine, the second week she just told me, ‘I am going to make appointments with people, I am going to look for a care facility for mom’ and that was a punch in the face, because it feels like you are abandoning your person.”]

Participant 4: *“Vir my was aan die begin die moeilikste ding om af te gee, om te sê, ‘Hoor hierso, hierso is my Pa, versorg hom asseblief’, waar hy altyd by my Ma was en hy en my Ma hulle het, het mekaar ondersteun, en ons was ook daar en so aan. So vir my was die moeilikste gewees om, ‘Okay, ek gee jou nou af na die*

mense en hulle moet na jou kyk'. Ja jy weet nooit wat rêrig gebeur nie, jy weet nooit rêrig slaan hulle hom, sluit hulle hom in die kamer toe, wat doen hulle, jy weet?" ["At the beginning one of the most difficult things for me was to drop him off, to say, 'Listen here, here is my father, please care for him', where he was always with my mother and him and my mother, they supported one another you know and we were also there and so on. So, for me that was the most difficult, 'Okay, I'm dropping you off and these people must look after you'. Yes, you never really know what is going to happen, you do not really know are they going to hit him, do they lock him up in his room, what do they do, you know?"].

Institutionalisation is a decision that is not made lightly. Once the adult children have made the decision to place their parent in a care facility they often have mixed feelings about their decision: on the one hand they are relieved that someone else is now taking care of their parent living with AD, on the other hand they often experience tremendous guilt for deciding to place their parent in a care facility (Sasoni, Anderson, Varona & Varela, 2013:236). Although it is a difficult decision to make, the adult child is forced to make decisions in the best interest of their parent living with AD.

5.2.2.1.2. Main theme 2: Placement of older parent in ADN Care Farm

AD is one of the most prominent reasons for the institutionalisation of older persons, and it has been documented that institutionalisation rates among those living with dementia are considerably higher than among older persons who enjoy good mental health (Colucci, Molino, Amenta & Gaeta, 2018:165). All ten adult children made the decision to place their parent with AD in the care of the ADN Care Farm. Although all participants had different reasons for placing their parents in the care facility, all stated that they do not regret their decision, appreciate the work that the care workers do and would encourage other families to consider placing their parent in the care of ADN.

Participant 1: *"Maar ek is my suster ewig dankbaar dat sy hierdie besluit geneem het, maar nogsteeds, dis 'n heavy stap. Somtyds as ek so alleen by die huis is, dan wonder ek, 'Hoe het ons dit reg gekry om hierdie stap te neem?' Maar ek is nooit, ooit spyt nie dat my suster daai stap geneem het nie."* ["But I am forever thankful that my sister made this decision, but it is still a heavy step. Sometimes

when I am so alone at home, then I wonder, ‘How did we manage to take this step?’ But I never, never regret it, that my sister took that step.”]

Participant 2: *“Oor haar op die oomblik, ek is nie bekommered, toe ek ver weggebly het, ja, maar nou wat ek naby is want my Ma is baie gesond, verskriklik gesond, en sy’s rustig en gelukkig.”* [“At this moment I’m, I’m not worried, when I lived far away, yes, but now that I am close, because my mother is very healthy, extremely healthy, and she’s calm and happy.”]

Participant 3: *“Ek dink nie daar’s meer mense veel geleerd in ons land as Berrie om dit te doen nie, weet jy? Kyk die mense wat by Berrie werk haal ek my hoed voor af wat elke oomblik saam met my Pa, agter my Pa hulle aanloop of sulke goed.”* [“I do not think there are people in our country who are more educated than Berrie to do this, you know? Look, I take my hat off to the people who work for Berrie who are with my father all the time, who walk after my father, things like that.”]

Participant 4: *“Nee, dis, dis, dis hartseer, dis baie hartseer en ek bedoel hy is nou by iemand anders en iemand anders kyk na hom. Maar ek, maar weet nou vir die feit hy is in goeie hande. Elke keer wat ek daar gekom het was hy goed versorg gelyk en hy is rêrig, hulle kyk mooi na hom.”* [“No, it is, it is, it is sad, it is very sad and I mean he is with someone else now and someone else is looking after him. But I, but I now know for a fact that he is in good hands. Every time that I have been there, he looked like he was well cared for and he was really, they really look after him.”]

Participant 5: *“Ek dink daai deel was vir my die moeilikste, maar anders as dit, ek moet sê ek haal my hoed elke dag vir Berrie en daai caregivers af, hulle doen ongelooflike werk.”* [I think that part was the most difficult for me, but other than that, I must say that I take my hat off to Berrie and those caregivers, they do unbelievable work.”]

Participant 7: *“Ja, ja nee ons is baie, ons is baie gerus. Ag en dis, dis wat wonderlik is van hom, hy bel jou dadelik as daar ‘n probleem is of as daar iets nie reg is nie,*

jy weet. Hy doen baie moeite.” [“Yes, yes, we are really, we are really at ease. Ag and that, that’s what great about him, if there is a problem, he calls you immediately, you know. He makes a lot of effort.”]

Cahill et al. (2012:18) assert that regardless of its cause, dementia is a progressive condition and deterioration is most likely to occur in all areas of the brain. Dementia is often an upsetting and terrifying disease for the individual living with it, and it can possibly be perceived as stigmatising and heartbreaking for family members (Cahill et al., 2012:18). Although people prefer to keep their elderly family member with dementia at home, long-term institutionalisation will still be required to deal with an ever-aging population and the increasing number of older persons who highly depend on others (Carmen, 2013:1630). Due to the many physiological, psychological and social changes that accompany old age, caring for older persons at home is a tremendous challenge and burden (Kunz, 2013:176), and as a result the family is often forced to make the difficult decision and place their parents in a care facility (Kloppers, van Dyk & Pretorius, 2015:247).

- **Sub theme 2.1: Slow progression of disease**

Participants made an appointment with their parents’ doctors once they started noticing a decline in their parents’ health and cognitive functions, which ultimately lead to the adult child’s decision to place their parent in the care of ADN. Participants stated that their older parent’s placement in the ADN Care Farm was further motivated by the slow progression of the disease and the immense deterioration in their parents’ health. Once they were informed that their parents were living with AD most participants started to become aware of the impact the disease had on their parents’ overall wellbeing. Although the decision to institutionalise was one that they did not make easily, the progression of the disease forced the hand of most of the participants.

Participant 1: *“Alles wat sy gedoen het het ‘n stadiger effek beginne kry. En die Sondagoggend, hier by die huis toe ek vir haar vra, ‘Maar hoekom het Mamma nou die rok aangetrek? Maar is fine, Mamma’. Sy het elke dag dieselfde rok aantrek en my Ma was baie lief vir, vir mooi aantrek en sy het pragtige pakkies gehad. Toe het sy vir haar opgeruk en kamer toe gegaan, en toe kom sy terug en*

sy het 'n sweetpak aan daai oggend en toe het ek besef hier is groot fout.” [“Her actions all became very slow. And the Sunday morning, here at the house I asked her, ‘But mom, why did you decide to wear that dress? But it is okay mom’. She wore the same dress every day and my Mom loved wearing beautiful clothes and she had stunning suits. She then got upset and went to her room, and when she got back, she was wearing sweatpants that morning and then I realised something is terribly wrong.”]

Participant 2: *“Die dokter het net gesê hy dink sy het Alzheimer’s want sy bel hom en sy kom na hom toe en dan twee dae daarna dan sal sy weer bel en kom en toe het ek my ma baie gebel altyd, en toe het ek agtergekom maar sy herhaal baie dinge vir my dieselfde en jy kom agter. Maar jy, ek dink jy wil ook nie agterkom nie, en jy dink dis maar net hierdie goed wat hulle vir jou dieselfde stories vertel en toe sê ek vir my ouer suster, ‘Jong ek weet nie of ek my verbeel nie, maar ek dink daar is fout met Ma’ en toe het my suster die dokter gebel en toe sê hy hy dink my Ma het Alzheimer’s.”* [“The doctor said he thinks she has Alzheimer’s because she would call him and then come to see him and then after two days she would call him again and come to see him again and then I always phoned my mother, and then I realised that she would constantly repeat the same things and you realise, I think you also do not want to realise it, and you think it is just this thing where they tell you the same stories and then I told my older sister, ‘I do not know if I am imagining it, but I think there is something wrong with Mom’ and then my sister called the doctor and he told her he thinks she has Alzheimer’s.”]

Participant 3: *“En een ding wat, wat ons besef het my Pa het hom uit alles onttrek. Okay my Pa was nog nie baie van sy lewe sosiaal nie. In sy jonger dae was hy sosiaal, maar nou, jy weet as ek nou sê van 2004 af het hy begin ... hy’t die een plaas verkoop, dit was net oornag besluit, ons het geen insae gehad nie, hy het die plaas verkoop. As jy vir hom eenvoudige goedjies gevra het, goed wat hy rêrig moet ken, karre of simpel goed, jy weet nou of boerdery goed, dan sal hy net sê nee maar hy weet nie, hy weet nie meer van die goed nie, hy kan nie meer dit onthou nie. En ook met diere, my Pa wat nou ‘n boer was sy lewe lank wat lief is vir diere, hy het bietjie moeilik met hulle begin raak en net heeltyd afgeknou en jy weet sulke goed.”* [“One thing that we, that we realised is that my father withdrew

himself from everything. Okay my father was never social much of his life, in his younger days he was social, but now you know if I say from 2004, he started ... he sold the one farm, it was an overnight decision, we had no input, he sold the farm. When you asked him simple things, things that he really should know, cars or simple things, you know like farming stuff, then he would just say no he does not know, he does not know about the stuff anymore, he can't remember. And also, with animals, you know my father that was a farmer his entire life who loved animals, he started becoming difficult around them and he started teasing them and you know stuff like that.”]

Participant 4: *“My Pa het begin geleidelik goeters vergeeet en jy weet en ons het agtergekem daar is iets nie meer baie lekker met hom nie en ons het agter gekem dat hy nie meer dieselfde is nie en toe het ons net besluit maar ons gaan hom maar laat diagnoseer.”* [“My father slowly started forgetting things and you know we started realising that something wasn't right with him and we realised that he isn't the same anymore and then we just decided that we will just have to have him diagnosed.”]

Participant 5: *“Ons dink natuurlik daai, daai hele situasie was die laaste spyker in die doodskis gewees vir my want, na my sussie se begrafnins het sy ongelooflike setbacks gehad soveel so dat sy letterlik in 'n kwessie van ses maande gegaan het van op haar eie bly, jy weet dat ons bekommerd is dat sy elke ete eet tot letterlik in die oggende opstaan en nie kan onthou of sy gisteraand tande geborsel het of nie. Sy sou nie by kon kom bly het nie, dit was maar iets wat ons moes besluit het, jy weet waantoe nou en waantoe gaan ons nou met haar?”* [“We obviously think that that, that that whole situation was the last straw on the camel's back because, after my sister's funeral she experienced incredible setbacks so much so that in a mere six months she literally went from living on her own, you know to us being worried that she was eating every meal to literally getting up in the morning and not being able to remember if she brushed her teeth last night. She wouldn't have been able to come live with me, so it was something we had to decide, you know where to now and where are we taking her now?”]

Participant 6: *“Toe ek met my Ma af Kaapstad toe gery het Desember tyd. Toe sien ek hoe eintlik erg dit geraak het. Oppad soontoe, toe sien ek hoe my Ma hom hanteer en toe ons in die Kaap was toe, toe ons my tannie daar gaan besoek het toe sien ek hoe sy hom bad, badkamer toe vat en selfs ek toe ons in die Waterfront was toe loop ons daar rond, my Ma vra my Pa moet nou toilet toe gaan, wil jy nie saamgaan nie, en dan gaan ek saam met hom toilet toe, toe sit ek hom in die toilet, jy weet daai hokkie in die toilet in, toe gee hy my sy skoene, toe gee hy sy broek, toe gee hy sy kouse, weet jy ek het eers begin panic, ‘Wat gaan nou hier aan?’ Ag en toe het ons ‘n lang gesprek daaroor gehad en besluit, nou my Ma kan nie meer na hom kyk nie. Of sy gaan en ons sit met my Pa of ons moet, moet ‘n keuse doen, en toe het ons besluit.”* [“When I drove down to Cape Town with my mother over December, that’s when I saw how bad it really got. On our way there I saw how my mother handled him and when we were in Cape Town, when we went to visit my aunt there, I saw how she bathed him, took him to the bathroom and even when we were walking around in the Waterfront. My mother said my father needs to go to the bathroom, do not I want to go with him, and I went with him to the bathroom, I put him in the toilet, you know those toilet cubicles, then he gave me his shoes, then he gave me his pants, then he gave me his socks yes, you know, I first started panicking, ‘Because what is happening here?’ Ag and then we had a long conversation about it and decided now my mom can’t look after him anymore. Either she is going to go, or we are going to sit with my father, or we had to, had to make a choice, and then we just decided.”]

The institutionalisation of an AD-affected relative is a painful decision which is frequently further discouraged by the scarcity of adapted facilities and the need of an economical contribution in case of institutionalization in private facilities not receiving public support (Colucci et al., 2015:169).

- **Sub theme 2.2: Physical and financial wellbeing of parent**

The researcher asked participants what finally forced their hand to place their parent in a care facility, and participants stated that apart from the slow progression of the disease their parents’ physical and financial wellbeing strongly contributed to their decision to place their parents in the care of ADN.

Participant 1: *“Die eerste wat ek mos nou maar aan gedink het, sy het alleen by die huis gebly, onmiddellik het ek besef my Ma sal nie meer kan kos maak nie, sy kan nie by die stoof ... ek kan nie rustig by die werk wees en my Ma moet kos maak, sy sal die kos verbrand. Behalwe dit, sy kan vir haar seer maak en as sy iewers heen gaan, sal sy die pad weer terug kry huis toe? Dit was my grootste vrese gewees.”* [“The first thing that I thought about, she lived alone in the house, immediately I realized that my Mother won’t be able to cook anymore, she can’t be by the stove ... I can’t be at peace at work and my mother must make food, she will burn the food. Except for that, she can hurt herself and if she goes somewhere, will she find her way back home again? That was my biggest fear.”]

Participant 2: *“Om vir my Ma by my suster te kry, ons het haar onmiddelik getrek want sy het alleen gebly neh, ons moes haar onmiddelik trek want, jy kan haar mos nou nie meer in ‘n woonstel laat bly nie. So ons het haar, die eerste ding wat ons gedoen het, ons het haar getrek Karibib toe. Toe het sy daar gebly en sy het nege jaar by my suster gebly voor sy Yakandonga toe is.”* [“To get my mother to my sister, we moved her immediately, because she lived alone hey, we had to move her immediately because, you can’t allow her to live in the apartment anymore. So, we, the first thing we did, we moved her to Karibib. She lived there and she lived with my sister for nine years before she went to Yakandonga.”]

Participant 3: *“Ja kyk die heel eerste ding, okay ek het oorgeneem met die finansies toe ons agterkom my Pa is, hy is nog dat hy nog sy handtekening kon doen, jy weet. Ek het testament gedoen, ekke het al die bank goeters, ek het volmag op my Pa en Ma gekry sommer van die begin af, om daai beheer te hê van alles. Toe, toe ook nou, ja toe hy nou dementia ... bestuurderslisensie en al daai goed. Ag die lisensie het ons gevat, maar daai wat ons moes sê, ‘Pa ry nie meer dorp toe nie’.”* [“Yes, look the first thing, okay I took over his finances when we realised that my father is, that he was still able to sign his signature, you know. I drew up the will and testament, I did all the bank things, I got full authority over my father and mother from the beginning to have that control of everything. Then, then also now, yes then the dementia ... driver’s license and all those things. Ag, the license we took, but we had to say, ‘Dad you cannot drive to town anymore’.”]

Participant 5: *“Ja, pretty much die leef, lewensomstandighede vir haar. Weereens dink ek dit het baie te doen met waar die brein eerste gaan en of sy nog selfversorgend is of nie. Ja en kort voordat ons haar getrek het, my sussie is in Juniemaand oorlede en daai Oktobermaand het sy die oggend gery wat sy net, wat sy heeltemal glad nie meer kon onthou waar sy is of waar sy heen moet gaan nie. Sy’t nou net glad nie geweet hoe om terug te kom by die huis nie en ek dink dit, dit was daar waar ons so half beseft het maar die goeters link nie meer by mekaar nie. So, leef definitief. Kyk dat sy eet, so dit het maar alles met die leef te doen. Onversorg, sy’t nie meer na haarself gekyk nie en dit het my begin bekommer want my Ma was altyd ‘n baie trotse vrou en ook nooit met ‘n kortbroek by die huis uitgegaan nie of ongewasde hare of sulke goeters nie en dit het my maar bietjie begin vang.”* [“Yes, pretty much the living, living circumstances for her. Again, I think it has a lot to do with the part of the brain that goes first and if she is still able to care for herself. Yes, and shortly before we moved her, my sister passed away in June and that October she drove one morning that she just, that she completely could not remember where she is or where she should go, she didn’t know how to get back home at all and I think it, it was there that we realised that things do not link together anymore. So, the living circumstances definitely. Make sure that she eats, so it all has to do with her living circumstances. Uncared for, she didn’t look after herself anymore and it started to worry me because my mother was always a very proud woman and never left the house with shorts or unwashed hair or stuff like that and that kind of affected me a little.”]

Participant 6: *“Die lewenstyl van hom. Hoe vinnig gaan hy teruggaan, wat is sy lewenstydperk wat hy gaan lewe?”* [“His living conditions. How quickly is he going to deteriorate, how long he is going to live?”]

Participant 7: *“Wel ons moes nou dink aan my Pa se dagroetine, ons moet hom nie te veel versteur nie, maar dit was ook nie altyd maklik nie, want hy het partykeer jy weet vreemd, snaakse goed gedoen en in die nag wakker geword soos daai keer wat hy nou die ongeluk gehad het of hy het begin rondloop buite. So dit is so half so nou en dan is daar so iets heeltemal uit die roetine uit wat gebeur, maar ons het hom maar so rustig gehou dat, dat hy sy daaglikse goedjies doen.”* [“Well

we had to think about my father's daily routine, we could not disrupt him too much, but it also wasn't always easy, because he sometimes did weird, funny things and woke up during the night like that time he had the accident, or he started to walk around outside. So, it was kind of like every now and then something happened that was outside his routine, but we kept him calm so that, that he could do his daily tasks.”]

Participant 8: *“Ons moes haar finansies en goeters moes ons onder ‘n struktuur ingekry het, want toe het sy nou van die plaas afgekom en die plaas verkoop en sy het ‘n paar woonstelle gehad, die woonstelle verkoop. So, ons het haar goed onder trustee gekry en ons het al haar bates onder die ding ingekry. Ons moes haar laat, jy weet sy het geteken dat sy nou ‘n trust het en sulke goedjies, dit moes ons doen.”* [We had to get her finances and other things under a structure, because she came from the farm and sold the farm and she had a few apartments, sold the apartments. So, we got her stuff under trusts and we got all her assets under the thing. We had to let, you know she had to sign that she had a trust and things like that, that's what we had to do.”]

Family caregivers often take on a broad number of care-related tasks when caring for an older parent with dementia, ultimately playing a fundamental role in supporting the functional independence and quality of life of older parent (Hainstock et al., 2017:37). Although these care-related activities ensure that older parents remain in their communities and homes for as long as possible, they are often forced to transition to care facilities, when their care needs become too complex (Hainstock et al., 2017:37).

- **Sub theme 2.3: Caregiver burnout**

Caring for a family member with AD is not an easy task, and it can have a damaging impact on the family caregiver's physical, psychological and emotional life, as well as on their social and financial lives (Colucci et al., 2015:169). Family caregivers carry an emotional 'backpack', also referred to in literature as the caregiver burden, and although the contents of the backpack differ from person to person each of them contains the heavy components of grief and stress (Barr et al., 2016:76). Available literature on dementia caregiving indicates that most caregivers describe feelings of

“helplessness, guilt, anger, frustration and social alienation” (Pattanayak et al., 2010:115). The burden caregivers carry is not only associated with an adverse emotional state and psychiatric ill health in the caregiver, but it also had a physical, financial and social implications (Paradise, McCade, Hickie, Diamond, Lewis & Naismith, 2015:73). In fact, when compared to non-caregivers, caregivers are far more likely to report “worse health, utilize medical care more frequently and take psychotropic medication” (Paradise et al., 2015:73). The decision to place their older parent living with AD in the care of ADN was further driven by the caregiver burnout experienced either by the adult child him- or herself or by their siblings. Caring for their older parent with AD had a severe impact on their physical, emotional and financial wellbeing.

Participant 2 stated that at the time of her mother’s diagnosis she was living in the Eastern Cape and her mother resided in Namibia, and as a result her sister was forced to take care of their mother. She acknowledged that caring for their mother was a tremendous task and burden for her sister to carry alone.

“En toe het my oudste suster vir Ma gevat na haar toe want my suster bly alleen. Toe gaan bly my Ma by haar en toe het dit vir haar te veel geraak. Sy kon nie, sy het nog gewerk, maar dit het net vir haar te veel geraak, sy kon dit nie meer handle nie, en toe het ons my Ma by Berrie gesit, in Yakandonge.” [“And then my oldest sister took mother in because, my sister lives alone. My mother then went to live with her and then it became too much for her. She could not, she still worked, but it just became too much for her, she could not handle it anymore, and then we placed my mother with Berrie, in Yakandonge.”]

“Toe my suster na haar gekyk het kon jy ook verstaan die frustrasie wat my suster gehad het. Onthou my suster het geen opleiding gehad om na haar te kyk nie en daai tyd was die tyd wat sy alles herhaal, want sy het geen afleidings gehad nie, daar was geen mense nie.” [When my sister looked after her you could understand the frustration that my sister had. Remember my sister had no expertise to look after her and that time was the time, she repeated everything, because she had no distractions, there were no people.”]

Although Participant 8 never physically took care of her mother after her AD diagnosis, as a result of the disease her mother's actions became repetitive and she was emotionally drained. The placement of her mother in the care of ADN and her mother's consequent behaviour was emotionally draining and exhausting.

“Dit was, dit was vir my horrible. Toe het sy nog ‘n selfoon gehad en sy het vir my, as ek vir jou sê tienkeer per uur gebel om te sê, ‘Kom haal my, ek wil nie hier wees nie, ek gaan myself dood maak’. Toe was sy nog redelik sterk gewees, en toe het ons op die einde van die dag na so twee weke, ek was amper vrek.” [“It was, it was horrible for me. She still had a cell phone then and she, if I tell you she called me ten times an hour to say, ‘Come get me, I do not want to be here, I am going to kill myself’. She was still reletavily strong then, and then at the end of the day after about two weeks, I almost died.”]

Initially, caring for their mother living with AD was a responsibility shared by Participant 10 and her sister. Their lives revolved around their mother's care needs and it became an exhausting cycle.

“Dit het toe nou gebeur dat my daaglikse roetine het in die oggende vier uur begin, dan gaan ek werk toe mos nou en dan is Nannie (Annie) en die vroujie nou alleen hier dan maak hulle nou vir Mamma skoon voor Nannie (Annie*) werk toe gaan en dan is die vroujie mos nou alleen met Mamma deur die dag en dan namiddae as ek van die werk af kom dan kom ry ek reguit hierna toe en dan moet ek nou vir Nannie (Annie*) help dan was ons vir Mamma en sorg dat sy eet en dat sy reg is vir die aand.”* [“It then happened that my daily routine started at four o'clock in the morning, then I go to work and then Nannie (Annie*) and the lady are here alone and then they clean my mother during the day and then in the afternoons when I came back from work then I drove straight here and then I had to help Nannie (Annie*) then we washed my mother and ensured that she ate and that she was ready for the evening.”]

“So hier teen middel Desember toe besef ons dat ons sal mos nie so kan aangaan nie, ons moet almal terug gaan werk toe en dan op die einde van die dag nogsteeds net Nannie (Annie) wat by die huis is.”* [“So here by mid December we realised that

we won't be able to carry on like this, we all have to go back to work and then at the end of the day it is still only Nannie (Annie*) who is at home.”]

Many of the adult children also made the decision to institutionalize their parent living with AD as they realised that their healthy parent was carrying a great care burden, which was negatively impacting their overall wellbeing.

Participant 3: *“Kyk vandat my Pa begin siek raak het was hy mos nou heelyd op die plaas gewees. My Ma het ‘n geval gehad wat sy so bietjie van ‘n mental breakdown gehad het. Sy was opgeneem in die hospitaal vir twee weke. So toe moes ek na my Pa gekyk het op die plaas. Toe kry ons ‘n dame in om na my Pa te kom kyk en dan ook sommer na my Ma te kyk. My Ma was in die sewentigs, die tannie wat na hulle gekyk het is ook in haar sestigs, so dis net te veel. Ja, daar trek ons die lyn.”* [“Look since my father started becoming sick, he was on the farm the whole time. My mother had an instance where she had a bit of a mental breakdown. She was admitted in the hospital for two weeks. So then, then I had to look after my father on the farm. Then we got a lady to come and look after my father and at the same time look after my mother as well. My mother was in her seventies, the lady that looked after them was also in her late sixties, so it is just too much. Yes, there we draw the line,”]

Participant 6: *“Dit het later oor my Ma gegaan want, ek het daar gestaan en dit was like ‘Sjoe, jy kan nie’ want my Ma het begin oud raak, rêrig oud. Jy het dit gesien aan haar liggaam en haar, in haar oë ook. Sy’t ook agteruit gegaan. Sy’t ook nie na haarself meer gekyk nie, meer na my Pa.”* [“It later became about my mother because, I stood there and it was like ‘Sjoe, you can’t’ because my mother started to get old, really old. You saw it in her body, and in her eyes. She also started to deteriorate. She also didn’t look after herself anymore, more after my father.”]

Participant 7: *“Toe hy nou begin siek raak het, het my Ma baie kans gesien daarvoor om hom te versorg op die plaas, maar ek dink dit was baie moeilik want hy, hy was maar moeilik en of ek dink, dit het sy tol begin eis op haar. Hy het eendag so snaakse ding oorgekom wat hy in die nag met sy kar ingery het daar op die plaas en oor ‘n bos gery het en amper verongeluk het, en ek dink daai, daai hele scenario, daai*

hele situasie wat gebeur het, het my Ma heeltemal laat knak. Sy het inmekaar gesak daarna en toe het ons agtergekom dit gaan nie moontlik wees vir my Ma om hom verder te versorg nie want dit, dis vir haar baie, baie erg en dis toe ons die besluit geneem het om vir Berrie te bel en vir hom oorteleplaas soontoe.” [“When he started to become ill, my mother was up for it to take care of him on the farm, but I think it was very difficult because he, he was difficult and, or I think, it started to take its toll on her. Something funny happened to him where he drove his car on the farm at night and drove over a bush and almost caused an accident, and I think that, that whole scenario, that whole situation that happened, it broke my mother completely. She had a breakdown after that and then we realised that it was going to be difficult for my mother to continue to care for him, because it is really difficult for her, really difficult and then we made the decision to phone Berrie and to place him in their care.”]

Participant 4 stated that at the beginning their mother was able to care for their father living with AD, but it became a tremendous burden as the disease progressed and as a family, they needed to step in to ensure their mother’s wellbeing.

“My Ma het mos saam met hom gelewe en so, ons het as familie saam besluit om dit te doen omdat my Ma hom nie meer kon hanteer nie. Dis hoekom ons besluit het hy moet in sorg kom waar mense wat weet wat hulle doen hom kan help. So ja, ons het hom gevat en my Ma het dit hanteer, ek dink my Ma het dit hanteer vir drie jaar, drie en ‘n half dink ek, amper vier en dan het sy, en dan het ek, het ons agtergekom ek en my broer, en ons het besluit, ‘Jy kan nie meer nie, jy kan dit nie meer hanteer nie en jy maak jousef ook nog stukkend,’ en ja ons moet ingryp en toe het ons ook weer gaan sit en dit bespreek, en toe het ons natuurlik besluit om hom in daai ander ouetehuis te sit.” [My mother lived with him and so, as a family we decided together to do it because my mother could not handle him anymore. That is why we decided that he must be in care where people who know what they are doing can help him. We took him and my mother handled it, I think my mother handled it for three years, three and half I think, almost four and she, and then I, we my brother and I realised, and we decided, ‘You can’t anymore, you can’t handle it anymore and you are damaging yourself,’ and yes we must step in and then we went and sit down again

and discussed it, and then we obviously decided to place him in that other old age home.”]

Caring for one’s older parents in their home environment truly burdens all persons involved (Shoenmakers et al., 2010:191). Family caregivers are often “on call 24/7” and consequently they are often sleep-deprived, overwhelmed and living in a state of chronic, constant stress (Barr et al., 2016:78). The impact of dementia on the family is often so severe that it alters family life and forces caregivers to face important changes in their lives, and dementia is often accompanied by severe deterioration in the physical and psychological state of family caregivers (León-Salas, Olazarán, Cruz-Orduña, Agüera-Ortiz, Dobato, Valentí-Soler, Muñiz, González-Salvador & Martínez-Martín, 2013:257). The caregiver burden intensifies along with the patient’s increased dependence and behavior disturbance, eventually advancing the patient’s institutionalization (León-Salas et al., 2013:257). Family caregivers often receive no training or support, and this places them at an even higher level of stress (Fulmer & Li, 2017:162). Additionally, these caregivers also suffer from huge financial burdens, which is somewhat due to disruptions in work, “as most caregivers must adjust their working schedule to care for their loved ones, and there are few employment policies protecting family caregivers” (Fulmer & Li, 2017:162). Pattanayak et al. (2010:115) similarly assert that as a result of the constant stress and strain of the caregiving process which has an adverse impact on the caregiver’s health, caregivers of an impaired older person have been referred to as the hidden patients.

- **Sub theme 2.4: Adult child has no support**

Mr. Berrie Holtzhausen, founder of ADN stated that he is not aware of any support services for the families of those living with dementia in Namibia. Participants were asked if there are any support services available to family members of people living with dementia, and they responded there are no support services available to them as the family.

Participant 11: *“Families van dementia mense is hier niks. Nee, hier is niks nie hoor, hier is niks.”* [“Families of people with dementia, there is nothing here. No, there is nothing here.”]

Participant 2: “*Glad nie. Op hierdie stadium is ek darem nou al daaroor weet jy? Maar ek dink vroeër sou ek, as ek net meer kon uitvind.*” [Not at all. At this stage I am over it already you know? But I think earlier I would have, if I could just have found out more.”]

Participant 3: “*Ja, jy het niks support nie, jy’t geen support system om te sê, ‘Bel hierdie ou, hulle gaan vir jou adviseer om dit te doen’ of ‘Jy kan hierdie mense kom bel, hulle sal inbly in jou huis vir ‘n tyd om jou te help’ of sulke goed.*” [“Yes, you have no support, you have no support system to tell you, ‘Call this guy, they will advise you what to do’ or ‘You can call these people, call them they will stay in your house for a while to help you’ or things like that.”]

Participant 5: “*Daar is definitief nie genoeg ondersteuning nie so ek begin ook onmiddellik dink maar hoe moet jy dit vir iemand oordra dat hy dit verstaan? Hoe breek jy dit vir iemand oop? Hoe wys jy dit vir iemand sonder om daai persoon wat Alzheimer’s het se hele menslikheid weg te vat?*” [“There is definitely not enough support so I also immediately think but how must you explain this to someone in a way that he understands? How do you crack this open for someone? How do you show someone without taking away the dignity of the person who has Alzheimer’s?”]

Participant 9: “*Glad nie, en mense weet nie wat om te doen nie, dokters weet nie.*” [“Not at all, and people do not know what to do, doctor’s do not know.”]

Participant 10: “*Daar is definitief nie genoeg support nommer een, en ook definitief nie genoeg centres in Namibia nie.*” [“There is definitely not enough support number one, and also definitely not enough centres in Namibia.”]

Informal caregivers provide most of the care for people living with dementia, and these informal caregivers often include spouses, adult children, daughters-in-law and sons-in-law and friends (WHO, 2015a:1). Regardless of pay, training, or relationship to a person with dementia, caregiving is often a lonely, stressful, thankless task. Many family care partners have little or no physical help or emotional support and sometimes no one to step in and give them a much-needed break (Barr et al., 2016:78). The role

of family caregivers is often not supported or properly acknowledged (WHO, 2015a:1). Research has shown that the unfortunate reality is that people living with dementia and their family caregivers are particularly susceptible to health care systems that either cannot recognise or meet their needs, and the consequences thereof can be devastating (Guerchet & Karagiannidou, 2016:52). The WHO (2015a:2) asserts that the caregiving and support of people living with dementia is not solely the responsibility of the family and others in the immediate network of the person with dementia, and that it should be a concern for “communities, governments and society as a whole”. However, the role of family caregivers is often not supported or acknowledged.

5.2.2.2. Care facilities for people living with AD in Namibia

Establishing best practices to improve the quality of life for PWD is quite problematic due to the complex nature of dementia, the diverse nature of the family, and the differing healthcare, social and welfare services across the country (Zabalegui et al., 2014:176). Globally dementia presents many challenges for primary care, and while early or timely diagnosis has received much attention the long-term management of the patient with dementia in primary care has been neglected (Wilcock et al., 2016:362). In Namibia there are many old age homes, but there are not nearly enough care facilities for PWD. Dementia is a complex disease that has a severe impact on the overall wellbeing of the patient, and as such PWD require specialised care to ensure that their complex needs are met. Unfortunately, there are not enough of these specialised services or care facilities available in Namibia.

5.2.2.2.1. Main theme 3: There is a lack of facilities specialising in Alzheimer’s care in Namibia

It has been argued that a ‘dementia friendly’ environment compensates for disability and should “consider both the importance for the person with dementia of his/her experiences within the environment and also the social, physical and organisational environments which impact on these experiences” (Innes, Kelly & Dincarslan, 2011:548). In Namibia there are very little dementia friendly environments or care facilities. Dr. Belinda Bruwer is a qualified psychiatrist with more than ten years experience, and she has been practicing in Namibia since 2015. Dr. Bruwer confirms

that there are not enough care facilities in Namibia for older persons living with dementia, and she states that, “Most dementia patients in private care are being cared for by family or frail care / old age units. I’ve encountered patients in my practice that were even neglected in private frail care units” (Bruwer, 2018/08/09). Participants strongly agreed there are not nearly enough care facilities or services available to those living with AD.

Participant 3: *“Not a hell. Nee sorry, nee. Nee, not a chance.”* [Not a hell. No sorry, no. No, not a chance.”]

When asking participant 4 whether she believed that there is a need for more facilities in Namibia, she agreed that there is a definite need for more specialised care facilities.

Participant 4: *“Ja ek dink so. Kyk die een daar, die een in Swakop is, is mooi. Ek dink mense moet so ene sê nou maar in Windhoek ook kry. Ja nee ek dink sulke fasiliteite moet ‘n mens ook miskien in Windhoek kry vir mense wat in Windhoek self is.”* [Yes, I think so. Look, that one there, the one that is in Swakop it is, it is nice. I think people should get one let’s say in Windhoek as well. Yes no, I think such facilities one must maybe also het in Windhoek for people who are in Windhoek.”]

Participants also added that apart from the fact that there are not enough care facilities available in Namibia those that are available are expensive and not all Namibians can afford to place their older parents in the care of these institutions.

Participant 2: *“Die ander ding is almal kan dit ook nie bekostig nie neh. Dis die groot ding, mense kan dit nie bekostig nie.”* [“The other thing is everyone can’t afford it hey. That’s the big thing, people can’t afford it.”]

Participant 3: *“Kyk ek het nie ‘n pyn oor die prys nie, maar dis ontsaglik duur, as ek kyk wat ek vir Berrie hulle betaal maandeliks om dit te doen, ek dink as daar meer sulke plekke is en goeters dan sal jy met kostes en goed baie beter hanteer word en as die staat dit meer kan subsideer vir mense met Alzheimer’s want dis ontsaglik duur.”* [Look I do not have a problem with the price, but it is extremely expensive, if I look at what I pay Berrie them monthly to do it, I think if there are more places like

this and stuff then you can handle the costs and stuff much better and if the state can subsidise it more for people with Alzheimer's because it is extremely expensive.”]

Participant 8: *“As jy geld het, ja. Nee, ek dink nie so nie. Daar is seker nie, as jy geld het is jy fine. Ek is jammer om dit so te sê, dis R11 000, R12 000 ‘n maand, verstaan jy? Ek is jammer, as jy geld het is jy fine, as jy nie geld het nie is dit vir jou nag. Maar ek verstaan dit, want dis absoluut jy moet iemand by jou, ek verstaan dit. Maar ek dink as jy nie geld het nie is dit vir jou klaar.”* [If you have money, yes. No, I do not think so. There probably aren't, if you have money then you're fine. I am sorry to say it like that, it is R11 000, R12 000 a month, you understand? I am sorry, if you have money you are fine, if you do not have money then it is hell for you. But I understand it, because it is absolutely you need someone with you. But I think if you do not have money then you are done.”]

Mr. Berrie Holtzhausen stated he was worried initially that if they established a care facility that caters for the specific needs of older persons living with dementia, they would essentially be removing these people from society and placing them in isolation which is what one wants to avoid. However, he stated that the unfortunate reality is that because societies do not know about the disease, older persons living with AD are often abused and neglected, and as such, specialised care facilities are needed.

“Nou gaan daar sulke mense weer tuisvoel in die gemeenskap. Jy weet dis hoekom ek altyd gewonder het moet ons hierdie plek begin, want nou haal ons weer die mense uit die gemeenskap uit, maar aan die ander kant as hulle nie hier is nie dan is hulle by hulle huise waar mense nie verstaan nie, waar hulle mishandle word. So jy moet heeltyd met daai ‘moet ‘n ou ‘n bubble skep’ want dis ‘n skep van ‘n bubble hierdie, todat die gemeenskap dit aanvaar soos enige ander siekte en ‘n terminale siekte wat eintlik verskriklik is want hy het geen cure nie, geen omdraai nie, dan sal die gemeenskap ook betrokke raak.” [Now those kinds of people will feel at home in the community. You know that's why I always wondered if we should open this place, because now we take the people out of the community again, but on the other hand if they are not here then they are at their homes where people do not understand, where they are abused. So, you need to constantly think about “must be create this

bubble” because this is creating a bubble, until the community accepts it like any other disease and a terminal illness that is actually terrible is because it has no cure, no going back, then the community will also become involved.”]

As the disease progresses it becomes more and more difficult to provide care for a loved one living with AD, and ultimately many people will require more care and assistance than their family members can provide (Dementia Care Central, 2018). According to Dementia Care Central (2018) even those older persons who do not require intensive hands-on care, safety may be an issue and they will not be able to stay home alone. In such instances residential care facilities, such as the ADN Care Farm, may be able to provide best for the needs of some individuals.

- **Sub theme 3.1: Participants struggled to find specialised care**

Family members are often afraid to place their parent in a care facility as these homes have been described as cold and boring. However, care homes have increasingly transitioned to create a homelike atmosphere hoping to make their residents feel more at home and expose them to the stimuli of normal life (Smit, 2017:3). However, in Namibia there are not enough of these kinds of facilities that provide specialised care for people living with dementia, and Participant 4 stated that they had difficulty finding a care facility that would be able to provide for their father’s special care needs. She further mentioned that in the first old age home in which her father stayed he was exposed to abuse and neglect. Participant 9 similarly stated that her mother received terrible care at the old age home in which she was initially placed and that it resulted in her mother’s condition deteriorating at a faster pace.

Participant 4: *“Ja, dit was nie maklik nie, want jy weet jy soek ‘n plek en jy weet nie of die mense rêrig goed na hom gaan kyk nie. Is hulle opgelei om na hom te kyk?”*
[“Yea, it wasn’t easy, because you know you are looking for a place and you do not know if the people will really look after him well. Are they trained to look after him?”]

Participant 4: *“Hy was okay in die begin ek was amper elke dag daar om hom uit te vat, want toe kon hy nog loop en hy’t nog so bietjie gesels en so aan maar dan so met die tyd het ek agtergekom maar hulle los hom in die kamer. Hulle stap nie meer*

met hom nie, en dan raak hy frustreerd en dan het hy begin frustreerd raak en dan het hy begin goeters stukkend maak. Hy het sy kas deure afgeruk, en sy gordyne afgeruk. Die dokter wat ons daai tyd gehad het het toe nou, ons het toe nou gesê maar moet nou nie pille voorskryf nie, want dit, dit gaan nie help nedit gaan nie help as jy vir hom allerhande pille voorskryf nie, want dit maak dit nie gesond nie en toe het sy dit nogsteeds gedoen. Toe het sy hom op een pil gesit wat hom nou heeltemal dat hy hand uitgeruk het. Hy het sy bed omgegooi, hy het in die hoekie gaan sit en dit was vir my erg. Ja, hy wou toe nie opstaan van die vloer nie en hy't, hy't agteruit gegaan en hulle het hom nie versorg rêrig nie. Hulle het hom rêrig nie versorg nie, ja so dit was erg. En die eendag wat ek toe natuurlik daar gekom het hulle hom vasgebind in die stoel en toe het ons besluit, nee kyk nou.” [He was okay in the beginning. I was there almost every day to take him out, because then he could still walk, and he still spoke a bit and so on but as time went on, I realise that they leave him in the room. They didn't walk with him anymore and then he got frustrated and then he started getting frustrated and then he started to break things. He ripped off his cupboard doors, he ripped off his curtains. The doctor that we had at that time did, we then told her not to prescribe him any medication because it would not help him, it won't help if you prescribe him all kinds of medication because it does not cure him and then she still did it. She then prescribed him one pill that made him completely lose it. He tipped his bed over; he went to sit in a corner and that was terrible for me. Yes, he didn't want to get up off the floor and he, he deteriorated, and they really didn't take care of him. They really did not take care of him, yes so that was difficult. And the one day that I got there they had tied him to a chair and then be decide, no look now.”]

Participant 4: *“So ek is tevrede nou, aan die begin was ek baie ontevrede want soos ek sê by die eerste plek waar hy was is hy half mishandle.” [So, I am satisfied now, at the beginning I was very dissatisfied because like I said at the first place where he was, he was kind of abused.”]*

Participant 9: *“My Ma en Pa het gebly in Gobabis en my Pa wou nie gehad het my Ma moet vêr van hom af weggaan nie, en sy is in Gobabis in die ouetehuis gesit. Sy het nie goed daar aangepas nie, maar behalwe vir dit waar ons eventueel die besluit gemaak het om haar te skuif is ons het daar ingekom en sy was met lakens*

vasgemaak aan 'n rystoel. Hulle het vir haar 'n doek aangesit, haar vasgemaak aan 'n rystoel en dis dit, gelos.” [“My Mother and Father stayed in Gobabis and my Father didn't want my Mother to go far away from him, and she was put in the old age home in Gobabis. She didn't adapt well there, but apart from that how we eventually made the decision to move her is that we came there, and she was tied to a wheelchair with a sheet. They put a nappy on for her, tied her to the wheelchair and that was it, they left her.”]

Participant 9: *“Sy was, weet jy op daai stadium dit het haar baie skade gedoen. Ek het haar gekry toe het sy gesit en wieg in die rystoel en sy kon nie 'n woord vorm nie. Sy was heeltemal, heeltemal deurmekaar gewees. Eventueel nadat ons vir haar Yakandonga toe gevat het sy actually verbeter. Binne 'n maand se tyd, maar net omdat die hantering. Ek dink hoe sy op daai stadium in Gobabis was was nie regtig haar toestand gewees nie, dit was die emosienele impak van wat met haar gebeur.”* [“She was, you know at that stage it did a lot of damage to her. I found her and she just sat there rocking in the wheelchair and she could not form a word. She was completely, completely confused. Eventually after we took her to Yakandonga she actually improved. Within a month's time, but just because of the way they cared for her. I think how she was in Gobabis was not really due to her condition, it was the emotional impact of what happened to her.”]

Participant 5 believed there are not enough specialised facilities in Namibia, and one will not receive enough support to open such a specialised care facility.

“Fasiliteitsgewys in Namibië is hier glad geen en al nie genoeg nie. Ek dink Berrie praat van 'n waglys van ek weet nie hoeveel mense wat na hom toe wil stuur nie. Jy het nie genoeg hande om dit te kan doen nie. Vir die tipe fasiliteit wat mens in jou drome wil oprig vir hierdie mense daar is ook nie genoeg ondersteuning nie want as jy nie fisies daarmee werk nie of iemand het wat naby aan jou is nie gaan jy nie kan verstaan wat dit is nie.” [Facility wise in Namibia there is definitely not enough. I think Berrie spoke of a waiting list of I do not know how many that people want to send to hom. You do not have enough hands to do this. For the type of facility that you want to erect in your dreams for these people there is also not enough support

because if you do not physically work with it or have someone close to you with it you won't understand what it is.”]

Participant 6 stated that he did some research once they made the decision to place their father in a care facility, and he only came across the ADN Care Farm which provides specialised care for people living with dementia in Namibia. *“Die enigste plek wat ek gekry het toe ek op die internet research gedoen het was Berrie. Hy was die enigste ou wat ek gekry het.”* [The only place I found when I did some research on the internet was Berrie. He was the only person that I found.”]

An increasing number of families are forced to pay large sums of money to care facilities when they can no longer provide the necessary care for their demented family member (Du Preez, 2016). Currently there is little prospect that a cure for dementia will be found, and as such maximizing quality of life (QoL) has gained increasing attention globally (Beerens, Zwakhalen, Verbeek, Ruwaard, Ambergen, Leino-Kilpi, Stephan, Zabalegui, Soto, Saks, Bökberg, Sutcliffe & Hamers, 2014:2). To ensure that maximum quality of life be attained for PWD more resources and specialized care facilities need to be established.

- **Sub theme 3.2: Not all homes for the aged can care for Alzheimer's patients**

According to the Healthy Aging Model of the WHO the care environment has an essential role to play in compensating for losses that are experienced by persons living with AD (Smit, 2017:3). Although people living with dementia often have severe physical or cognitive limitations their functional ability and overall level of wellbeing can be maintained when they live in a supportive environment (Smit, 2017:3), and as such the quality of the physical environment is essential to ensure that the person's wellbeing is not compromised. Equally important is the social environment, which focuses on the various psychological needs of the PWD such as autonomy, identity, enjoyment, security and relationships (Smit, 2017:3). PWD have a magnitude of physical and psychological needs which cannot be met by medical staff and care workers who are not educated on providing specialised care for these patients. As a result, not all old age homes have the ability and the expertise to care for a PWD. Participant 6 responded not all old age homes are equipped and able to meet the

special care needs of people living with AD. *“Jy kry hierdie ouetehuse soos die ene wat in Okahandja is, hulle sê hulle kan kamstig dit hanteer, maar ek dink nie hulle nog rêrig daarmee te doen gehad nie.”* [“You find these old ages homes like the one in Okahandja, they say they can apparently handle it, but I do not think they’ve really been exposed to it.”]

Participant 7 told the researcher that she knows of an old man who was moved from old age home to old age home and he was just never happy or well care for until he was placed in the care of ADN. She further agreed with other participants that there is a dire need for more care facilities in Namibia that know how to deal with the specific care needs of people living with Dementia. *“Nee, ek dink nie so nie. Berrie stoei baie alleen. Berrie hulle het nou ‘n oom gekry, ‘n ouerige oom wat ooral in Windhoek was. Hulle het hom, hy was net nooit gelukkig nie, hulle het hom net baie sleg hanteer en hy is nou so gelukkig by Berrie. So ek dink Berrie veg maar baie alleen.”* [No, I do not think so. Berrie really fights this alone. Berrie them just got a gentleman, an older man who has been everywhere in Windhoek. They, he was just never happy, they just treated him very badly and he is now so happy with Berrie. So, I think Berrie is really fighting alone.”]

Participant 10 answered although she knows of a care centre in Windhoek, she does not believe that they do not provide the specialised care needed to care for older persons living with AD. *“Daar is definitief nie genoeg support nommer een, en ook definitief nie genoeg centres in Namibia nie. So ver ek weet is Nonidas wat na Alzheimer’s pasiente omsien en daai tyd wat ons uitgevind het was daar ‘n centre in Windhoek ook, maar hulle spesialiseer nie in Alzheimer’s mense nie.”* [Number one there is not enough support, and not enough centres in Namibia. So far as I know it is Nonidas that looks after Alzheimer’s patients and that time we found out there was a centre in Windhoek as well, but they do not specialise in people with Alzheimer’s.”]

5.2.2.3. People living with AD require specialised care

As the disease progresses the individual with dementia will need a great deal of personal and specialised care, care which family members are often not able to provide. During the early stages of AD, families may opt for home care so that their

loved remains in familiar surroundings and enjoy as much independence as possible (Wegerer, 2019). Wegerer (2019) continues to state that as the disease progresses, and the older parent requires 24-hour care which can only be found in a specialised care facility such as the ADN Care Farm.

5.2.2.3.1. Main theme 4: The ADN Care Farm provides specialised care

One of the primary predictors of institutionalisation is the ongoing burden that caregivers and family members experience as the patient's condition deteriorates and care needs increase over time (Sasoni et al., 2013:236). In 2015, the WHO published the World Report on Ageing and Health in which a new model of Healthy Aging is defined (WHO, 2015:28). Healthy Aging is defined as 'the process of developing and maintaining functional ability that enables wellbeing in old age' (WHO, 2015:28), so that people can continue to be and to do what they value in life (Smit, 2017:6). With the new Healthy Aging model in mind, WHO has called upon care facilities to take responsibility for the wellbeing of the PWD in their care as PWD are entitled to live in a supportive physical and psychological environment where their basic human rights and needs are addressed (Smit, 2017:6). The ADN Care Farm has embodied a human-rights and person-centred approach to caring for PWD. Each patient is treated as an individual who has individual needs and wants, and each patient is treated with the utmost respect to ensure that their dignity and individuality are protected.

- **Sub theme 4.1: ADN Care Farm caters for the physical needs of residents**

During the first few stages of AD, persons experience some loss of memory and require little assistance; however as the disease progresses caregivers and family members of someone living with AD are often forced to deal with the person's severe personality and mood changes and they have to attend to the physical needs of someone who is now completely dependent on them (Sasoni et al., 2013:236). As the disease progresses and the older parent becomes completely dependent on the care of others, the adult child experiences great difficulty in meeting the parent's physical care needs. The adult children in this study all have their own families and many responsibilities. An AD diagnosis has a major life impact on the family and care giving is often a very difficult and physically demanding task that engulfs the caregiver's life. Participants

indicated that at the ADN Care Farm their parents receive the specialised physical care that they are unable to provide to their parents.

Participant 1: *“Mamma is nou al soos ek gesê het amper twee jaar daar, nog nie op ‘n dag as ons daar kom het my Ma na urine geruik nie. Nog nie op ‘n dag nie. En dis nie asof ons daai mense vooraf sê ons kom besoek môre vir Mamma nie, jy kan agterkom dis ‘n normale roetine wat hier plaasvind, daaglik.”* [“Mom, as I said has now been there for almost two years, my Mother has never smelled like urine anytime we go there, not one single day. And it is not like we tell those people beforehand that we are going to visit Mom tomorrow you can see that it is a normal routine that takes place, daily.”]

Participant 4: *“Maar ek, maar weet nou vir ‘n feit hy is in goeie hande. Elke keer wat ek daar gekom het, het hy goed versorg gelyk en hulle kyk goed na hom”* [“But I, but I know for a fact that he is in good hands. Every time that I went there, he looked well cared for and they look after him well.”]

Participant 6: *“Hulle kyk baie mooi na hom. Ons kan enige tyd daar opdaag. Ek het vroeg oggend daar opgedaag en die mense wat daar werk, sien hoe baie professioneel hulle dit hanteer en baie oulik nogal.”* [They really take good care of him. We can show up there at any time. I showed up there early morning and the people that work there, I see how very professional they handle it, actually very ‘cute’.]

Participant 8: *“En dan by dominie Berrie hulle natuurlik jy hoef nie eers te bel nie. Ag jy moet nou nie belaglik wees en seker in hulle slaap tydjie daar aankom of so nie, maar jy hoef nie ‘n afspraak te maak om my Ma te sien nie. My Ma was nog nooit onversorg nie, regtig en ek het op die weirdeste tye daar aangekom.”* [“And then obviously at pastor Berrie them you do not even have to call. Ag you shouldn’t be unreasonable and probably go there during their nap time or so, but you do not have to make an appointment to see my Mother. My Mother has never been un-cared for, really and I have arrived there at the weirdest times.”]

Participant 10: *“Mamma is versorg, daar waar sy is kry sy haar kos op tyd, sy word gebad op tyd, daar’s iemand wat vir haar nasien.”* [“Mom is well cared for, there where she is, she gets her food on time, she is bathed on time, there is someone who looks after her.”]

- **Sub theme 4.2: ADN Care Farm allows adult children to live their lives without worrying about their parents’ wellbeing**

When looking at major life changes, such as an AD diagnosis in an older parent, from a systems’ perspective it is easy to see that when an individual or couple come face to face with these life changes there are consequences throughout the family system (Cowan & Cowan, 2016:430). An AD diagnosis often causes a change in the roles of different family members, as the adult children or spouses suddenly find themselves in the roles that they did not envision such as caregiver or advisor, and transitions such as these threaten to disrupt the normality within the family (Cowan & Cowan, 2016:430). Due to the consuming nature of AD, adult children are often forced to place their own lives on delay while they put all their time and energy into caring for their parent with AD. Specialised facilities such as ADN Care Farm allow children to live their lives knowing that their parent is in good hands and receiving the best care. Participant 1 stated that she is incredibly thankful for the care her mother receives at the ADN Care Farm, and the knowing that her mother is in good hands allows her to live her life fully without guilt and worry. *“Daar is baie kere wat ek vir die Here dankie sê vir hierdie, vir hierdie sentrum. Ek kan dit nie, nie genoeg promote by ander mense nie. Hulle is regtig hands on. Miskien sou die versorging die selfde gewees het, ek kan verkeerd wees, maar ek is rêrig uit my hart uit dankbaar vir hierdie sentrum wat so naby is en mense wat uit hulle pad uit gaan. Soe hierdie sentrum was vir my ‘n antwoord uit die hemel gewees, en ek is vry om te kom en gaan soos ek wil want ADN het vir my daai vryheid gegee. Nou het ek die wereld se tyd want my Ma is in goeie versorging, sy is veilig”* [“There are many times that I thank God for this, for this centre. I can’t, I can’t promote it enough to other people. They are really hands-on. Maybe the care would have been the same, I might be wrong, but I am so grateful for this centre that is so close and people that go out of their way. So, this centre was an answer from heaven and, I am free to come and go as I want, because ADN gave me that freedom. Now I have the world’s time because my mother is in good care, she is safe”].

Both Participants 6 and 7 that they never worry about the care their fathers are receiving at the ADN Care Farm.

Participant 6: *“Nee, ek is glad nie. Waar hy nou is, is ek glad nie. As daar iets is, ek weet Berrie bel dadelik.”* [“No, I am not at all. Where he is now, not at all. If there is something, I know Berrie will call me immediately.”]

Participant 7: *“Ja, ja nee ons is baie, baie gerus. Ag en dis, dis wat wonderlik is van hom, hy bel jou dadelik as daar ‘n probleem is of as daar iets nie reg is nie, jy weet. So dit is, hy doen baie moeite.”* [“Yes, yes no we are very, very at peace. Ag and it is, what’s wonderful about him, he calls you immediately if there is a problem or if there is something that’s not right, you know. So it is, he puts in a lot of effort.”]

Participant 10: *“My Ma lewe, my Ma is versorg daar waar sy is, sy is vrede. Solank as wat sy versorg is, is ons ander vrede.”* [“My Mother is alive, my Mother is cared for there where she is, she is at peace. If my mother is cared for, we are at peace.”]

Participant 10 similarly indicated that they never worry about their mother’s care or wellbeing as they know she is well cared for, and she would truly encourage people to place their older parent living with dementia in the care of ADN as it allows one to live out your own life and ensures that your parents’ wellbeing is catered for.

“En ek sal regtig waar, ek is die een wat vir mense aanbeveel, ‘Vat julle se mense dat hulle versorg word. Moenie dat julle se lewens verby julle gaan omdat julle die las dra van iemand, maar daar is iemand wat die versorging kan waarneem nie’. Maar ons is mos hierso en ons kom mos elke naweek by Mamma en ek voel ons betaal mos vir versorging, so ons het nie nodig om daar te gaan sit heel dag nie. Nee, ons het reeds vir Mamma daar gaan gelos omdat ons wil aandag gee aan ons families.” [“And I will really, I am the one who encourages people, ‘Take your people so that they are care for. Do not let your lives pass you by because you carry the burden of someone else, but there is someone that can supervise the care. But we are here, and we go see my Mother every weekend and I feel that we pay for her

care, so we do not need to go sit there the whole day. No, we left Mom there because we want to give attention to our families.”]

5.2.2.4. Support received when older parent was placed in ADN Care Farm

The decision to institutionalize an older parent is difficult and often accompanied by many negative emotions such as guilt. When the adult child makes the difficult decision, which they believe is in the best interest of their parent, to place their parent living with dementia in a care facility they need support from other family members, friends and the broader community. However, often this decision is met with criticism and a lack of support. According to Zimmerman, Dobbs, Roth, Goldman, Peebles and Wallace (2016:535) when an individual is surrounded by people who have negative attitudes or opinions about an older person receiving care in a supportive care environment, whether these attitudes are justifiable or not, it is less likely that this individual will gladly initiate or accept such care or support.

5.2.2.4.1. Main theme 5.1: Participants received support during the Alzheimer’s journey and their decision to institutionalise

Failing health and frailty often require older people to make changes in their living environments, either by making changes to their current residence or by relocating to a more supportive environment such as a care facility (WHO, 2015b:36). Although many families are often left with no other choice but to place their older relative in a care facility, institutional settings are often perceived as dehumanizing and as posing structural and cultural barriers that hamper social interaction (WHO, 2015b:36). The decision to institutionalise is one that families do not make lightly, and participants stated that receiving support from other family members, friends and the community made it easier for them to make such a difficult decision.

Participant 1: *“In die gemeente is daar regtig ‘n baie groot ondersteunings meganisme, seker oor die feit dat my Ma was baie betrokke in die gemeente, betrokke lidmaat, en even ons familie was, is baie betrokke, maar op die einde van die dag dink ek ook maar net dis guns uit God se hand. Daar is die wat, wat vir ons grief gee, ja, oor Mamma wat moet terugkom huis toe. Maar dan moet ek ook sê*

80% ondersteun ons in hierdie besluit wat ons geneem het” [“In the church community there is really a very big support mechanism, probably about the fact that my Mother was a very involved member in the church, an involved member, and our family was, is very involved and, but at the end of the day I think it was favour out of God’s hand. There are those that, that give us grief, yes, about my Mother that must come back home. But then I must also say that 80% support us in this decision we made.”]

Participant 4: *“As familie staan ons altyd bymekaar en ons probeer altyd mekaar help en so aan. Ons het net meer bymekaar gekom en net jy weet, en ja ons het probeer mekaar net help en ja, ons was maar nog altyd close gewees en om my Ma ook te help het ons ook maar meer ingespring en meer gaan kuier vir my Ma.”* [“As a family we have always stood together and try and help each other and so on. We just grew closer to each other and just you know, yes we tried to help one another and yes, we were always close and in order to help my mother we all came together to help out more and we went to visit my mother more.”]

Participant 5: *“Gelukkig is my man baie ondersteunend met dit gewees, ook omdat hy dag tot dag met my Ma te doen gehad het.”* [“Luckily my husband was very supportive with this, also because he interacted with my mother daily.”]

Participant 7: *“Ek moet nogals sê ons het baie goeie ondersteuning gekry van ons familie.”* [“I must say that we received a lot of support from our family.”]

Participants received support from their families, spouses, friends and religious institutions. Being surrounded by people with positive attitudes, who attempted to understand why the adult child made the decision to place their parent in a care facility and who showed their support made it easier for the adult child to ultimately adjust. This clearly assisted in the decision to place their parents in an institution.

5.2.2.4.2. Main theme 5.2: Participants experienced lack of support through criticism

After diagnosis, the need for support is high, but next of kin often feel abandoned and in need of emotional support (Kjällman-Alm et al., 2013:1). The findings suggest that adult children of PWD need support for some time to adapt to the fact that they lost a parent who is still alive. To alleviate feelings of depression and burden, family members ought to receive counselling and support during and after the institutionalisation of their parent (Sasoni et al., 2013:244). The adult children should be offered support groups as a means of crisis intervention. They should therefore have the possibility to talk about how they feel in a nonjudgmental environment with others in the same predicament in the presence of a skilled moderator who can answer any questions. They also need information about the disease and the process of diagnosis and treatment to feel like they are part of the process as well as understand the behavior and needs of their parent to be a more skilled caretaker (Kjällman-Alm, 2013:7).

Participant 1: *“Ons kry dit nou nog. Daar is baie mense wat bel wat close aan ons is wat vra, ‘Wil julle nie julle se Ma vir ‘n naweek gaan haal?’ Ek het byvoorbeeld nou, seker ‘n maand gelede met iemand gepraat wat vir my gevra het, ‘Wil julle nie maar julle se Ma terug bring huis toe nie?’”* Ons sien mos nou die agteruitgaan elke dag soos wat ons daar kom. Haar woorde was, *‘Wil jou Ma nie maar in die huis kom sterf nie?’ Dit het nou al ‘n paar keer gebeur. My redenasie is my Ma ken ons nie meer nie. My Ma weet sy is in ‘n beskermde environment. Sy weet nie of dit huis of versorgings sentrum is nie, sy weet net sy word versorg. My vraag aan hierdie vriendin was, ons kan haar terugbring maar wat dan van die versorging? En haar presiese woorde was, ‘Julle kinders kan mos onder mekaar reël’. Ek sê, ‘Okay, my sussie is in Suid Afrika sy is predikant daarso; my broer werk in Oranjemund; my ander broer en sy vrou is hierso, hulle het voltydse werke; my sussie werk buitekant Swakop, ook ‘n voltydse werk, ek het ook ‘n voltydse werk. Hulle sal kom om te kom help, maar wat dan van hulle se huwelike en hulle se kinders? Wat gebeur met hulle?’ Oh, dan kan sy my nie antwoord nie.”* [“We still get it today. There are people that call that are close to us who ask, “Do not you want to go get your mother for the weekend?” For example, probably a month ago I spoke to someone who asked me, ‘Do not you want to bring your mother back home?’ We see the deterioration

everyday when we go there. Her words were, 'Does not your mother want to pass away at home?' It has happened a few times. My argument is that my Mother does not know us anymore. My Mother knows she is in a protected environment. She does not know if it is her house or a care centre, she just knows that she is being cared for. My question to this friend was, we can bring her back but what about her care then? And her exact words were, 'You children can arrange among one another'. I said, 'Okay, my sister is in South Africa, she is a pastor there; my brother works in Oranjemund; my other brother and his wife are here, they have full time jobs; my sister works outside Swakop, also a full-time job, and I also have a full time job. They will come help, but what about their marriages and their children? What happens to them?' Oh, then she can't give me an answer.”]

Participant 5: “*Omdat mense nie verstaan wat in jou immediate sirkel aangaan nie, dis die wyer kring van mense se persepsie van wat jy met daai, hoe jy daai persoon hanteer en hoe soos ek wat nou my Mamma in 'n fasiliteit het. Ek het ongelooflik baie, ek kan nie vir jou vertel hoe baie negatiewe kritiek ek gekry het oor mense wat haar geken het toe sy nog in Windhoek gewerk het of wat ookal. So verskriklik baie mense het my negatief en kwalik geneem oordat ek my Ma in so fasiliteit laat bly twerwyl daar eintlik niks fout is met haar nie en dit was vir my moeilik om mense se persepsies te bestuur en vir mense te verduidelik dat die persoon wie julle ken of geken het nie meer daar is nie want dit is vir my hartverskeurend dat mense jou wat geensins 'n idee het waardeur jy gaan nie, nie probeer om te verstaan nie, daai is moeilik en dit is nie lekker nie. Ek dink daai gedeelte was vir my die moeilikste.*”
[“Because people do not understand what is happening in your immediate circle, it is the broader circle of people's perceptions of how you handle that person and how I now have my mother in a facility. I received a tremendous amount; I can't tell you how much negative criticism I received from people who knew her when she still worked in Windhoek or whatever. So many people were negative and blamed me because I placed my Mother in such a facility while there is actually nothing wrong with her and I found it difficult to direct people's perceptions and to explain to people that the person who you know or knew is no longer there because it is heartbreaking that people that have absolutely no idea what you are going through, who do not try and understand, that is difficult and it is not nice. I think that part was the most difficult for me.”]

Participant 9 believed they received no support from the people around them when they decided to place her mother in a care facility and that people criticised them for their decision. *“Oh ja, oh ja, oh ja! Ek is baie sleg gesê, my Pa is baie sleg gesê van, ‘Watse tipe man is jy? Hoekom sit jy jou vrou in ‘n plek in? Kan jy nie self vir haar versorg nie? Hoe sleg is jy?’ Baie.”* [“Oh yes, oh yes, oh yes! I was really insulted, my Father was really insulted, ‘What kind of man are you? Why did you place your wife in a facility? Can’t you take care of her yourself? How bad are you?’ Very.”]

In many societies and cultures adult children are expected to care for their elderly parents (Stuifbergen & Van Delden, 2011:63). These expectations often originate from the adult children themselves, their older parents, other family members and community members (Stuifbergen & Van Delden, 2011:63). Participant 10 stated that as a family they are still criticised, and people often judge them for placing their parent in a care facility. *“Yes, nou nog. Nou nog. Daar is baie van die groot mense wat vra ons moet vir Mamma gaan haal en terug bring huis toe ek sê vir hulle reguit, ‘As julle vir Mamma wil gaan kuier dit staan julle vry om vir my te sê ‘My kind, ons wil Saterdag vir Mamma gaan kuier kan jy vir ons vat daarna toe? Ek het ‘n bakkie en ek het ‘n toe kar, ek sal altwee karre vat en julle almal laai om vir haar te gaan kyk, en as ons haar klaar gekyk het dan kom ons almal weer huis toe en sy bly agter’. Maar ons kry verskriklik teenstand, even van onse eie oom, my Ma se enigste broer wat nog lewe, hy was glad nie vir hierdie dat ons haar daarna toe vat nie en ek dink hy verwyt ons regtig, hy verwyt ons kyk tot in die afgrond in omdat ons sy suster daarna toe gevat het. Die ander groot mense, dis nou groot mense soos in die gemeenskap, daar is regtig baie teenstand maar ek voel, persoonlik voel ek dis omdat hulle nie verstaan watter sorg my Ma nodig het nie.”* [“Yes, even now. Even now. There are many older people that ask that we must go pick up my mother and bring her home, I tell them straight, ‘If you want to go visit my mother then you are welcome to tell me ‘My child, we want to go visit your Mom on Saturday can you take us to her? I have a bakkie and a sedan, I will take both cars and pick everyone up to go visit her, and when we are done visiting her then we all go home, and she stays behind’. But we get tremendous resistance, even from our own Uncle, my mother’s only brother that is still alive, he didn’t support us in taking her there and I think he really resents us, he resents us into the abyss because we took his sister there. The other older people, that’s the older

people in the community, there is really a lot of resistance, but I feel, personally I feel it is because they do not understand what care my mother needs.”]

- **Sub theme 5.2.1: Participants experienced that AD and the care centre carries a stigma**

Some of the most stigmatised and socially excluded members of society are individuals living with dementia (Henwood & Downs, 2014:20). When considering dementia, stigma has an impact on several aspects, including the PWD’s willingness to seek a diagnosis and to look for support once diagnosed (Swaffer, 2014:709). People with dementia are forced to cope and adapt to their cognitive and physical impairments, and the discrimination and stigma they are confronted with daily make their already difficult battle even more difficult and traumatising (Henwood & Downs, 2014:20). Family members of the PWD often face the same discrimination and they are likely to be socially excluded along with their loved one living with dementia (Henwood & Downs, 2014:20).

Participant 1: *“En seker ook, kan ‘n mens sê stigma wat daaraan kleef? Weet jy ek, ek myself het agtergekom mense is skaam. Mense is skaam om met hierdie siekte geassoieer te word.”* [“And probably also, can one say there is a stigma attached to it? You know, I myself realised that people are embarrassed. People are embarrassed to be associated with this disease.”]

Participant 2: *“Maar ek word baie kwaad as iemand praat van die plot as ‘n malhuis, ek word baie kwaad. Al is dit my familie of enige iemand, dis nie mal mense nie want ek, ek kuier elke week daar en ek leer ken mos al daai mense, hulle verbaas my dat daar is iets binne en jy dink hierdie persoon is weg.”* [“I get very angry when people speak about the plot as a mad-house, I get very angry. Even if it is my family or anyone, they are not crazy people because I, I visit them every week and I get to know all those people, it surprises me that there is something inside and you think this person is gone.”]

When Participant 7 was asked if she believes there is still stigma attached to AD, she said that although there is a better understanding of the disease, a lot still must be done to remove the stigma attached to AD.

“Ja, ek dink in ‘n mate ja. Ek dink dis al beter, maar dit is nog nie wat die moet wees nie.” [“Yes, I think to a certain extent yes. I think it is better, but it still isn’t what it should be.”]

Participant 9 believed people have a misperception about dementia and although many feel the PWD suffers and does not have quality of life she believes that her mother was happy, well cared for and she did not suffer.

Participant 9: *“lets wat my baie upset het toe my Ma oorlede is dat mense sê, ‘Nou is sy verlos, sy suffer nie meer nie’. Dit het my baie upset want ek dink nie sy het so ge suffer nie, ek dink nie dit was vir haar hel gewees nie. Ek dink sy was gelukkig. Ons verstaan dit nie en ons sien nie hoe kan sy gelukkig wees in daai prentjie nie want ons het klomp ander stimulant nodig om gelukkig te wees, sy het nie daai stimulant nodig om te kan gelukkig wees nie. So ek glo nie sy het ge suffer nie en ek dink dis ‘n groot misconception, wanpersepsie.”* [“Something that really upset me when my Mother passed away is that people say, ‘Now she is free, she is not suffering anymore’. That really upset me because I do not think she really suffered, and I do not think it was hell for her. We do not understand it and we can’t see how she can be happy in that picture because we need many other stimulants to be happy, she does not need those stimulants to be happy. So, I do not believe she suffered, and I think that is a big misconception, misconception.”]

Henwood and Downs (2014:20) assert that family members of a person living with dementia experience what they refer to as “courtesy stigma” and discrimination, and this often leads to social exclusion and depleted support systems at a time when support is most needed. This could be because friends and extended family members withdraw; families avoid public contact to protect the PWD from embarrassment or ridicule; and as a result of their caring responsibilities the family’s opportunities to engage socially become restricted (Henwood & Downs, 2014:20). Swaffer (2014:710) emphasises that stigma affects more than just well-being and quality of life for people

with dementia and their families, and without positive change stigma will remain a weighty burden on people with dementia.

5.2.2.5. Impact of AD on relationships

The impact of dementia is not limited to the person living with the disease. By nature, intimate and family relationships are complex and ever changing, and a diagnosis of dementia and the progressive symptoms of the disease will nearly always result in relationships being different and even more complex (Miskovsk, 2017:1). As the disease progresses the individual living with dementia and their family members will experience a variety of challenges and relationships will change (Miskovsk, 2017:1). Whether positive or negative, all participants experienced some change in their relationships with their older parent, siblings and other family members.

5.2.2.5.1. Main theme 6: Alzheimer's disease has an influence on relationships

A significant characteristic of human society is that individual lives are entwined through social relationships (Yang et al., 2016:578). Everyone maintains several interpersonal relationships on a day-to-day basis with some relationships momentary, such as a once-off interaction with the petrol attendant, while other relationships are more substantial such as the parent-child relationship (Van Deventer & Mojapelo-Batka, 2013:162). Human beings do not grow and develop in isolation; people form parts of larger systems and it is within that context that individuals develop and establish their identity (Beckett & Taylor, 2010:129). Whether momentary or long-term, AD has an impact on all relationships.

As previously stated, relationships are complex and as the disease progresses and the person's condition deteriorates relationships are either strengthened or negatively impacted. Participant 1 responded although dementia forced them to place their mother in a care centre, the relationship between herself and her siblings have become much stronger. *"Yes absoluut. Weet jy hierdie ding het gemaak dat ons nader aan mekaar gegroei."* ["Yes absolutely. You know this think made that we grew closer to each other."]

Participant 2 stated that since her mother's diagnosis their relationship is much stronger than ever before, and she believes their relationship is better now than it was a few years ago. "*Ja, presies. Nou is dit vir my baie beter as tien jaar gelede.*" ["Yes, exactly. Now it is much better than it was ten years ago."]

- **Sub theme 6.1: The AD diagnosis has an impact on sibling relationships**

AD impacts relationships in both positive and negative ways. AD is a family disease and affects the entire family system and friend circle of the person living with dementia (Barr et al., 2016:35; Woolsey, 2013:197). Depending on who becomes the main caregiver of the affected parent, the children can experience more closeness or conflict between each other. "Most family members discover closeness and cooperation as they work together to care for someone with dementia. Sometimes, however, pressures of caring for an impaired person create conflicts in families or cause old disagreements to flare up" (Woolsey, 2013:200).

Participants reported that AD had both a positive and negative impact on the relationships between siblings. Most participants replied that since the AD diagnosis, the bond between siblings has strengthened. Participant 1, Participant 7 and Participant 10 all stated that although AD is a terrible disease, in the end it brought the siblings closer.

Participant 1: *Ek kan rêrig sê Mamma se siekte het vir ons nader aan mekaar gebring, die band tussen broers en susters is absoluut hegteer.* [I can really say that my Mother's illness brought us closer to each other, the bond between brothers and sisters is absolutely stronger.]"

Participant 7: *"Dit het nogal, dit het nogal. Ek en Johan was nou nogal redelik in die selfde mindset as ek dit so kan sê. Peter is nou so bietjie anders dit was vir hom ek dink erger om te verwerk en hy het half kwaad geraak hy, dit was vir hom verskriklik moeilik. Dis asof hy half net toe my Pa nou opgeneem is half vrede gemaak het, dis klaar jy kan niks daarmee doen nie. Waar ek en Johan het soos nog so bietjie, ons probeer nog kyk of jy weet dat daar ekstra wat jy nog kan kry uit my Pa in die sin van jy weet die erken of die bietjie onthou en so, maar ek moet sê dit het ons drie*

nogal baie nader aanmekaar gebring.” [“It did kind of, it did kind of. Me and Christo (Johan) have always kind of had the same mindset if I can say it like that. Wessel (Peter) is a bit different I think it was more difficult for him to work though and he became kind of angry, it was very difficult for him. It is like he kind of made peace when my Father was admitted that it is done, and you can’t do anything about it. Where Chris (Johan*) and I still, we still try and get that something extra out of my Father in the sense of the recognition, the little remembrance or so, but I must say that it brought us three much closer to each other.”]

Participant 10: *“Ons het definitief baie nader aanmekaar gekom. Uhm, ek moet rêrig vir die Here dankie sê ons het, ons het rêrig waar baie nader aanmekaar begin leef. Ons kan baie meer openlik met mekaar gesels en na mekaar luister. Ek dink dit is die beste wat eintlik uit hierdie hele situasie gebeur het. Ons kan as siblings rondom die tafel sit en sê, ‘Maar jy het my seer gemaak, ek hou nie van dit wat jy gedoen het nie’ en ons kan dit uitpraat onmiddelik en alles is oor. So ja, ons het rêgtig ‘n baie beter verhouding. Even met skoonsus of swaer, die verhouding is regtig baie beter, en ek dink ons het baie meer empatie vir mekaar, vir mekaar se gevoelens.”* [“We definitely grew much closer to each other. I must really thank God that we, that we really started living closer to each other. We can talk to each other openly much more now and listen to each other. I think it is the best that happened from this entire situation. We can sit around the table as siblings and say, ‘But you hurt me, I do not like what you did’ and we can talk through it immediately and everything is sorted. So yes, we really have a beter relationship. Even with my sister in law or brother in law, the relationship is better, and I think we have more empathy with each other, for each other’s feelings.”]

Participant 2 was not sure if the relationship between herself and her sister had become stronger since their mother’s diagnosis. However, she did state that she had to force her sister to visit their mother and she later decided that her sister would have to willingly visit their mother on her own.

“Ek het haar saamgesleep Walvis toe. My Ma het siek geword toe is sy hospitaal toe, toe het ek my suster saamgesleep en dis die laaste keer wat sy my Ma gesien het. Maar okay, sy het ook daarna het sy siek geword, sy het borskanker gekry maar

dit is nie 'n verskoning, want jy kan nogsteeds gaan kuier. Maar sy sê nogsteeds vir my as ek haar bel sê sy, 'Gee soentjies en drukkies' en sulke goed, maar ek weet nie." [I dragged her to Walvis with me. My Mother became ill and then she went to the hospital, then I dragged my sister along and that's the last time she saw my mother. But okay, after that she also became ill, she got breast cancer, but it still isn't an excuse, because you can still go visit. But she still tells me when I call her, 'Give hugs and kisses' and stuff like that, but I do not know."]

Participant 3 similiary stated that he can't really say whether the AD diagnosis has had a positive or negative effect on the relationship between himself and his siblings. Participant 3 mentioned that at the beginning there was a lot of tension between him and his brother, but that they are now at a better place

"Aanvanklik aan die begin was dit baie tension. Dis nie lekker 'n lekker topic om oor te gesels nie, want dis die plaas, en wat gaan nou met die plaas, en Pa en daai goed. My suster was verskriklik lief vir my Pa vir haar vang dit nogsteeds baie. Ek en my broer kom nou meer beter oor die weg as wat ons doer-die-tyd gehad het, maar nou, jy's nou in dit, jy's nou heel in dit. My suster, ek kan nie sê, ag tussen my en my suster het ons, ons is nog fine, ons was nog altyd fine daaroor, dit was nou maar net die onsmaklikheid as jy dit opbring jy weet." ["Initially, at the beginning there was a lot of tension. It is not nice it is not a nice topic to speak about because it is the farm, and what's now going to happen to the farm, and my Father and those things. My sister really loved my Father, it still affects her a lot. My brother and I get along better now than what we did that time but now, you're in it now, you're completely in it. My sister, I can't say, ag between me and my sister we, we are still fine, we have always been fine about it, it is now just unpleasant when you bring it up you know."]

Participant 8 stated that the AD diagnosis did not really have an impact on her relationship between herself and her sister, because they have never really been close. Furthermore, herself and her sister live in different towns and do not see one another often.

“Kyk, ek en my sussie is nie, ons druk mekaar nie om elke hoe ken draai nie. Ek is baie lief vir haar, maar sy’s baie anders as ek. Ek weet nie of dit die situasie was nie, ek weet nie. Nie rêrig nie hoor, nie rêrig nie.” [“Look, my sister and I are not, we do not hug each other around every corner. I love her a lot, but she is very different than I am. I do not know if it was the situation, I do not know. Not really, not really.”]

Participant 9 similiary stated that due to the distance between herself and her sister the AD didn’t really have an impact on her relationship with her sister. Her sister moved to a different country about 18 years ago and they do not see each other often. However, she did state that her sister expected her to tell her how she should react to their mother’s diagnosis and that made it difficult for her.

“Ja, seker 18 jaar daar rond, so ons is nie regtig so, fisies close naby mekaar nie. Wat dinge vir my baie moeilik gemaak het met my suster is sy het van my verwag, ek is miskien lelik as ek dit sê, sy het op ‘n stadium van my verwag om vir haar te sê hoe sy moet reageer as ek dit so kan stel.” [“Yes, probably about 18 years, so we are not really so, physically close to each other. What made things very difficult for me is my sister she expected me, and maybe it is mean if I say it, at a stage she expected me to tell her how to react if I can put it that way.”]

Barr et al. (2016:35) state that AD severly tests relationships and is weighed down with the possiblity to totally derail them, and not all family ties stand to the end of the Alzheimer’s journey.

- **Sub theme 6.2: AD impacts the relationship between the adult child and older adult**

AD has proven to influence interpersonal communication, affecting the parent-adult child relationship (Woolsey, 2013:199). People with AD eventually lose the ability to uphold his or her side of a relationship which often results in relational trauma and forces the emotional connection between them and others into choppy and uncharted waters (Barr et al., 2016:35). The unfortunate reality is that AD has a disconnecting effect on the relationship between spouses as well the relationship between the older parent living with AD and their adult child (Barr et al., 2016:46). Stuijbergen & Van

Delden (2011:69) state that it is not fair for one to completely end a relationship with someone who cannot consciously contribute to the relationship due to the disease. The content of the relationship will undoubtedly change, but that does not justify ending the relationship completely (Stuifbergen & Van Delden, 2011:69).

Although AD often has a negative effect on the parent and child relationship, Participant 2 is of the opinion that the disease has brought her and her mother closer. She chose to continue building a relationship with her mother even though her mother cannot contribute to the relationship the way she did before AD. She further stated that she now cherishes the moments she has with her mother and that their relationship is stronger now than it was ten years ago.

“En dis die ander ding, ek neem, elke keer ‘n foto van haar. Ek dink altyd, ‘Sê nou maar dit is die laaste keer”. Ek kan nie vir jou vertel hoeveel fotos het ek nie. Elke week neem ek en dan dink ek, ‘Sê nou maar net dit is nou die laaste keer wat ek haar sien’. Dit kan net so gebeur, want sy is 89 amper, dit kan gebeur oornag. Ek is bly dat dit 16 jaar gevat het as drie jaar, dan sou ons nooit closer gehad het nie, maar nou het ons ‘n lang pad met haar gestap en sy het nou so rustig geword en ons kuier nou so lekker en ons lag met mekaar en maak grappietjies(grappies). Dis nou ‘n lekker tyd vir my, dis net vir my my Ma het Alzheimer’s nie, dis vir my my Ma is in ‘n ouetehuis, so voel dit vir my. Nou is dit vir my baie beter as tien jaar terug. Ek beplan nou al vooruit, ek en Ma gaan hierdie week dit doen en dit doen en ons gaan lekker lag en ons gaan dit gesels en sulke goedjies. Nou is dit ‘n fees.” [“And that’s the other thing, I take a photo of her every time. I always think, ‘What if this is the last time’. I can’t tell you how many photos I have. Every week I take, and I think, ‘What if this is the last time that I see her’. It can happen just like that, because she is almost 89, it can happen overnight. I am glad that it took 16 years rather than three, then we would never have had closure, but now we have walked a long road with her, and she has now become so calm and we have such good times together now and we laugh with each other and we make jokes. It is a nice time for me now. For me it is not like my mother has Alzheimer’s, for me it is that my Mother is in an old age home, that’s how I feel. Now it is much better than ten years ago. I now plan, this week my mother and I are going to this and we’re going to do this, we’re going to laugh and we’re going to chat and stuff like that. Now it is a blast.”]

Participant 7 similarly stated that in her opinion her relationship with her father is much stronger now than it was before the diagnosis.

“Nee wat, ek dink eintlik het dit ons sterker gemaak. Ja, nog sterker. Ons het ‘n verskriklike goeie verhouding ja.” [“No, I think it actually made us stronger. Yes, much stronger. We have an incredibly good relationship yes.”]

Participant 5 stated that she had an incredible relationship with her mother but since the diagnosis their relationship has deteriorated, and although she is still her mother’s daughter there is no longer a mother-daughter relationship.

“Ek en my Ma se verhouding, ek kan vir jou op my hand noem hoeveel keer ek en my Ma baklei het en dit was alles oor, oor kritiese goeters en die laaste vyf fights was oor watse kleur beker sy wil hê maar jy weet ons het ‘n ongelooflike verhouding gehad. So dit was vir my moeilik om aan die begin te besef dat ek verloor my Mamma, my beste vriendin, my confidant, my finansiële adviseer, my career advicer, my parental advisor, alles in een net weg. So, nee daar’s geensins ‘n verhouding meer nie. Ek het nog die naam van haar dogter en sy weet ook ek is nog haar dogter, maar verhoudings gewys wat mens het, nee.” [“My mother and my relationship, I can count the number of times that my Mother and I fought and it was all about, about critical things and the last five fights was about what color cup she wants, but you know, we had an incredible relationship. So, in the beginning it was difficult for me to realise that I am losing my Mom, my best friend, my confidant, my financial advisor, my career advisor, my parental advisor, everything in one just gone. So, no there is no longer a relationship. I still have the name of her daughter and she still knows I am her daughter, but relationship wise that one has, no.”]

Participant 8 mentioned that her relationship with her mother has changed so dramatically that she can’t share her heart with her mother anymore, and that she is forced to remember her mother for who she was because the disease has changed her completely.

“Ja, ek bedoel ek kan niks met haar deel nie. Dis eintlik verkeerd, ek moet dit net deel dat ek dit oor my hart of uitkry, maar verstaan jy? Ek bedoel my kinders sit voor haar dan vra sy, ‘Wie is julle tweetjies nou weer? Maar dit het my aan die begin nogals gepla, maar dit pla my glad nie meer nie. Jy moet die goeie behou, jy moet want sy het regtig baie verander. My sussie beskou dit verskriklik emosioneel dat sy ons nie meer erken nie, maar dit help nie want ek sê altyd vir haar, ‘Onthou as sy normaal oud geword het soos ander oumense of soos normale ou mense oud word sou sy dit nie wou gehad het om ons nie te erken nie,’ verstaan jy? Dis ‘n siekte. Dis nie asof sy lelik met ons is nie.” [“Yes, I mean I can share nothing with her. It is wrong, I must just share it so that I can get it off my heart, but do you understand? I mean my children sit in front of her then she asks, ‘Who are you two again?’ But in the beginning, it bothered me a lot, but it does not bother me anymore. You need to hold on to the good, you must because she has really changed a lot. My sister is very emotional because she does not recognise us anymore, but it does not help because I always tell her, ‘Remember if she aged normally like other old people or aged like other normal old people, she wouldn’t have wanted to not be able to recognise us’, do you understand? It is an illness. It is not as if she is being mean to us.”]

Regarding her relationship with her mother, Participant 9 stated that the AD diagnosis made her more selfish, she wanted more time with her mother because she realised that time was not on their side.

“Ja, dit het my meer selfsugtig gemaak. Ek wil nog tyd saam met haar wees. Selfsugtig is seker nie die regte woord nie, maar skielik het jy herinnering dat tyd kosbaar is. Ek het besef ek het nie meer, hoeveel tyd het ek nog? Hoeveel tyd het ek nog? En ek het geswot in Suid Afrika en ek het daar begin werk, so ek het daar ge stuck, verstaan en skielik het ek net besef ek het net soveel tyd saam met my Ma oor en ek moet dit nou gebruik of ek verloor dit. Dit is nie anders met enige ander ouer nie, dis net met Alzheimer’s sien jy dit, dit is hier.” [“Yes, it made me more selfish. I want to spend more time with her. Selfish is probably not the right word, but you suddenly have a reminder that time is precious. I realised that I do not have, how much time do I still have? How much time do I still have? And I studied in South Africa and I started to work there, so I became stuck there, understand and suddenly

I started to realise that I only have so much time left with my mother and I must use it now or I lose it, and it is not different with any other parent, it is just with Alzheimer's you see it, it is here.”]

While everyone is unique, dementia severely effects the language capabilities of people living with the disease and consequently affects their ability to communicate (Alzheimer's Society of Canada, 2016b:2). The severe deterioration of language is known as aphasia, and individuals with aphasia find it difficult to express themselves, find the correct words, and understand the words that are spoken to them. (Alzheimer's Society of Canada, 2016b:2). As the disease progresses, communication can become increasingly challenging.

- **Sub theme 6.3: Adult children experience an immense sense of loss**

Along with the changing relationship between the older parent and child comes an immense sense of loss and grief (Alzheimer's Society of Ireland and the Irish Hospice Foundation, 2015:2). Throughout the disease trajectory, caregivers often find themselves grieving losses that transpire while they provide care for their loved one's needs (Romero, Ott & Kelber, 2014:395). Predeath grief is believed to result from losses in the “quality of the original relationship, roles, well-being, intimacy, health status, social interaction, communication, and opportunities to resolve issues from the past” (Romero et al., 2014:395). Participants experienced an immense sense of loss and grieved their parents who are still alive, and they mentioned that there are a lot of things in their lives that have changed since their parents' diagnosis and that they feel like their parents are missing out on a lot of things, they are no longer part of important life events such as birthdays or Christmas and it is difficult to deal with.

Participant 1: *“Sy het by my gebly in die huis. As ek op my bed lê en my deur staan oop en sy lê op haar bed dan kan ons mekaar sien en dit was onse geselstyd. Dan sê sy ook, ‘Jy moet nog môre gaan werk, ons moet nou klaar maak’. Ja, dis nie meer daarso nie en jy mis dit. Ek het nou al twee moedersdae gehad wat, wat ek nie by die huis was nie en dis ook ‘n manier hoe die Here my voorberei dat as dit Moedersdag is en sy is nie meer die dag daar nie, dan sal ek dit kan hanteer.”* [“She lived with me in the house. If I lay on my bed and my door was open and she lay on

her bed, then we could see each other and that was our time to chat. Then she also said, 'You must still go to work tomorrow, we must finish up now'. Yes, that's not there anymore and you miss it. I have had two mother's days that, that I wasn't at home and I think it is also a way that God prepares me that when it is Mother's Day and she is no longer there, then I will be able to handle it."

Participant 2: *"Ek het vanoggend gedink, 'Wat is vir my die slegste daarvan?' Dat ek haar nie meer kan gaan haal nie want sy is nou in versorging, ek kan haar nie versorg nie en dat ek haar nie meer kan gaan haal dat ons Kersfees almal saam kan deurbring nie. Weet jy, as my kinders nou met hulle klein kinders en almal hierna toe kom, ons kan nie vir ouma hierna toe bring nie want ouma is nou in doeke en al daai goete. Dis net jy kan haar nie meer hierna toe bring nie en ja, dis bietjie moeilik, want dis eintlik lekker om, om aan 'n groot tafel te sit met 'n ouma en 'n oupa en oumagrootjie en almal bymekaar."* ["I thought this morning, 'What is the worst for me?' That I can't go fetch her anymore because she is in a care facility now, I can't look after her and that I can't go fetch her anymore so that we can all spend Christmas together. You know, if my children all come here with their small children, we can't bring granny here because granny is now in diapers and all those things. It is just you can't bring her here anymore and yes, it is a little difficult, because it is actually nice to, to sit around a big table with a granny or grandfather and a great grandmother and everyone together."]

Participant 5: *"Daar was 'n tyd toe ek nog met haar kon geskerts het oor die kinders, vertel het of sê dit gaan nou so of so, maar sy vra glad nie meer na hulle nie en as sy vra dan, sy weet daar is kinders, maar sy weet ook nie hoeveel, hoe oud of so nie."* ["There were times that I could still chat to her about the children, told her or tell her that it is going like this or so, but now she does not ask about them at all and if she asks then, she knows there are children, but she does not know how many, or how old they are or so."]

Participant 6: *"Hy was hands-on ja, hy was baie hands-on. Die tyd as ek sy hulp nodig gehad het, sê nou maar oor 'n kar engine, 'Pa nou dit doen so' of 'Dit doen dit, wat kan die fout wees?' Jy weet dit, dit het ook deur my kop gegaan, 'Wie gaan ek nou vra oor problem?'"* ["He was hands-on yes, he was very hands-on. Times

when I needed his help, let's say about a car engine, 'Dad it is doing this' or 'It is doing this, what can be wrong?' You know that, that also went through my head, 'Who am I now going to ask about a problem?'"]

Participant 7: "*Dit is nogal erg jy weet, en almal sê mos vir jou jy moet onthou die persoon wie hy was, dis moeilik. Hy's mos nou fisies, hy sit hier voor jou en hy kan niks vir jou gee nie. Hy wil nie, hy staan op en loop weg.*" ["It is pretty bad you know, and everyone tells you that you must remember the person for who he was, it is difficult. He's physically there, he sits in front of you, but he cannot give you anything. He does not want to, he gets up and walks away."]

Participant 3 stated that his relationship with his father was negatively impacted by the AD and the effect thereof on his father. He misses sharing his ideas with his father and he grieves the fact that he is unable to ask his father for advice in any area of his life.

"Kyk ons het nog altyd nie 'n maklike verhouding met my Pa gehad nie, hy is 'n kwaai ou, kwaai ou stoer ou boer. Ek dink die, die grootste terugslag is ek kan, ek kon nooit vir my Pa advies vra nie, jy weet van 2010 wanneer hy nou rêrig agteruit gegaan het en jy weet, ek het nou my eie besigheid en goeters, ek kon nooit vir Pa advies gevra het nie, enige iets nie, jy weet. Kyk my Pa is baie lief vir engins en karre en goed, ek dink ek het al seker vyf, sewe karre opgebou en weer verkoop, jy weet en dit is iets wat jy glad nie meer kan deel nie en iets wat ons belang in gehad het, en wat hy ook in belang gehad het. Vir my vang dit ook, my Pa het al die ander kleinkinders nog ontmoet maar hierdie ene kan hy nie ontmoet nie en hy sal ook nooit weet nie. In daai opsig sal ek sê is dit baie sleg." ["Look we have never had an easy relationship with my Father, he is an angry (strict) guy, an angry (strict) old boer. I think the, the biggest drawback is I can't, I can never ask my Father for advise, you know as from 2010 when he really started deteriorating, and you know, I now have my own business and stuff, I could never ask my Father for advise, anything you know. Look, my father loves engins and cars and stuff, I think I have modified about five, seven cars and sold them, you know, and it is something you can't share at all anymore and something we had in common, and that he also had an interest in. It gets to me too; my Father met all the other grandchildren but this

one he can never meet and he will also never know. In that context I will say it is really sad.”]

Participant 8 mentioned that she feels incredibly guilty that she can't invite her mother to her daughter's wedding or that she can't have her mother over for Christmas anymore. She misses the part her mother played in the family and she misses talking to her about life.

“Weet jy daar kom situasies wat vir my baie erg is en dan gaan dit weer verby. Soos my jongste dogter trou nou in November maand. Nou sy trou op die olyfplaas, maar ek bedoel dit is soos, wat is dit van my Ma af? Vyf kilometer? Ek kan haar nie vat nie. Kersfees raak nie lekkerder nie. Partykeer wil jy mos net jou Ma bel en sê, ‘Hey, weet jy ek is nou vandag in ‘n strond bui’, maar jy kan nie.” [“You know what, there are situations that come up that are very difficult for me but then they pass again. Like my youngest daughter is getting married now in November. Now she is getting married on the olive farm, but I mean it is like, how far is it from my mother? Five kilometres? I can't take her. Christmas does not get any better. Sometimes you just want to call your Mother and say, ‘Hey, you know today I am just in a crappy mood’, but you can't.”]

Participant 10 mentioned that her mother's AD diagnosis her love and empathy towards her mother has become stronger.

“Ek is baie lief vir haar. My Ma se eienskap van ‘n Ma is eintlik soos wat ek is, baie hard en ek het uit en uit dit van my Ma geërf, maar omdat my Ma nou so vulnerable is kan ek definitief sê my empatie en my liefde teenoor my Ma het baie meer dieper geraak as wat dit was toe ek jonger was. As gevolg van hierdie toestand wat sy nou, die Alzheimer's wat sy het, daar is regtig ‘n ander tipe verhouding tussen ons twee. Obviously kan ons dit nie, kan sy nie in woorde dit vir my sê nie, maar jy kan tog die diepte sien in haar oë.” [“I love her much more. My Mother's characteristic as a Mother is a lot like mine, very tough and I definitely inherited that from my Mother, but because my Mother is so vulnerable now, I can definitely say that my empathy and my love towards her has grown much deeper than it was when I was younger. As a result of this condition that she is in now, the Alzheimer's that

she has, there is really a different type of relationship between us. Obviously, we can't, she can't tell me it in words, but you can see the depth in her eyes.”]

Grief is a response to loss. If someone close develops dementia, we are faced with the loss of the person we used to know and the loss of a relationship (Alzheimer's Society of Canada, 2017). It is common for people to have feelings of loss and grief as their life and the life of the person they care for, is changed by dementia. These changes can have a significant impact on you and on other family members. You are likely to experience feelings of grief as the illness progresses. It can be helpful to recognise that this is normal when a person in your family has dementia and that it is important to look after yourself in relation to these experiences (Alzheimer's Society of Ireland and the Irish Hospice Foundation, 2015:1). To be able to look up to your parents as role models and use them as a template for how you deal with the world at any age is essential to the individual's personal growth (Kjällman-Alm et al., 2013:2).

- **Sub theme 6.4: Adult children grieve the changes that AD brought about in their parent's**

Apart from the immense loss that AD brings, adult children mentioned that the parent they know now is not the parent they knew before the AD diagnosis. They realise that it is the disease that has caused their parents' personalities to change, but they miss the parent they once knew. Barr et al. (2016:76) assert that people with AD gradually lose the ability to do things for themselves, to relate to others, and to remember who they are. With each of the losses that the person living with dementia experiences, family members lose something too: “the personality of the loved one that has made the relationship unique; the companionship of the person; and the future that had been planned with the loved one” (Barr et al., 2016:76, 77). Loved ones mourn the diagnosed person's deteriorating “cognition, changing personality, and behaviour” (Barr et al., 2016:77).

Participant 4 grieved the loss of the man she knew her father to be, although he was still physically present in their lives, he was not the same man that raised her and with whom she had a relationship.

“Ek bedoel ek het groot geword met my Pa wat alles doen van A tot Z en nou ewe skielik kan hy nie meer ‘n skroewedraaier optel en ‘n skroefie indraai nie. So dit was nogal ‘n skok. Jy raak groot met, met iemand wat alles kan en dan ewe skielik is dit net weg. Ons het baie dinge saam gedoen en so aan. Ja, ek mis hom want hy was ‘n baie grapperige persoon en hy, hy het goedjies met ons gedoen. Dit is nogal wat ek baie keer mis. Maar ja, soos ek sê ek mis hom nogal jy weet, omdat hy aan die begin ook met my dogter en my broer se twee kindertjies ook altyd gespeel het en so aan, jy wil tog hê jou kind moet ‘n oupa hê, jy weet?” [“I mean I grew up with my Father who did everything from A to Z and now suddenly he can’t pick up a screwdriver and fasten a screw. So that was quite a shock. You grow up with someone who can do anything and then suddenly, it is just gone. We did a lot of things together and so on. Yes, I miss him, because he was a very funny person and he did things with us. That is something I often miss a lot. But yes, like I said I miss him, because at the beginning he also played with my daughter and my brother’s two children and so on, you want your child to have a grandfather, you know?”]

Participant 6 stated that he wanted his children to know his father, he wanted them to have a relationship with his father but due to the debilitating nature of AD his father is no longer the man he once was.

“Ek wou gehad het hulle moet sien wie my Pa is want ek was trots op my Pa, hoe hy die goedjies gebou het. Hy’t nie ons entertain nie, maar hy het altyd ons lewens gelukkig gemaak.” [“I wanted them to see who my Father is because I was proud of my Father, how he always built things. He didn’t entertain us, but he always made our lives happy.”]

Participant 7 stated that although her father might have aged and changed physically, he is still her father, but she misses the relationship they had.

“Ek dink hy is nog die persoon wie hy was. As jy hom voor jou sien, hy dra nog sy hoedjie en lyk nog soos altyd dis net sy geheue. Hy is vir my nog daar, maar dit is nou net, ek sien hom altyd as die Pa wat ek ken, dit is nou net hy weet nie wie ek is nie as ek dit so kan sê.” [“I think he is still the person he was. If you see him in front

of you, he still wears his cap and looks like he always did, it is just his memory. For me he is still there, but now it is just, I always see him as the Father that I know, it is just now he does not know who I am if I can put it like that.”]

Participant 9 asserted that her mother’s entire personality and character changed, but until the day her mother passed away, she still saw and loved her as her mother.

“Persoonlikhede verander en hulle dink anders, hulle reageer anders, hulle hele karakter raak anders. Maar weet jy wat, die laaste wat ek my Ma gesien het, sy kon nie meer praat nie, sy’t omtrent glad nie oogkontak gemaak nie sy het nie acknowledge dat daar iemand by haar is nie. So sy het nie reaksie gewys nie, en daai heel laaste dag het ek vir haar gesê ek is lief vir haar en sy het gereageer daarop en daar het ‘n traantjie gekom. Sy het geweet wie ek is.” [“Personalities change, and they think differently, they react differently, their character changes. But you know what, the last time I saw my mother she could not speak anymore, she barely made any eye contact, she didn’t acknowledge that there was someone with her. So, she didn’t show any reaction, and that very last day I told her I love her, and she reacted to it and a tear formed. She knew who I was.”]

AD results in severe deterioration as the disease progresses. Participant 10 mentioned that during the last year of her mother’s life she found it very difficult to go and visit her at the care facility, because the woman that they placed in the care facility is not the mother she knew before AD set in. It was difficult for her to see her mother deteriorate more and more each day.

“Persoonlik is dit vir my baie moeilik om vir Mamma te gaan visit want persoonlik voel ek die mens wat daar sit is nie my Ma nie, dis ‘n liggaam wat daar sit. Maria Letta Maggot (Die Ma) wat ek geken het kon met my praat, sy kan vir my hallo sê, sy kan vir my sê, ‘Moenie so maak nie,’ sy kan met my ‘n gesprek voer, maar die mens wat daar sit is nie my Ma nie en uit respek uit gaan ek na my Ma toe, maar as dit van my af hang sal ek nie gaan nie want ek voel. Ek is emosioneel slegter af as ek daarvan af kom, dis te veel. Die baggage is te veel.” [“For me personally it is very difficult to go visit my Mother because personally I feel that the person sitting there is not my Mother, it is just a body seated there. Maria Letta Maggot (The mother)

that I knew could speak to me, she could say hello to me, she could tell me, 'Do not do that', she could hold a conversation with me, but the person sitting there is not my Mother and out of respect I go visit my Mother, but if it was about me I wouldn't go to see her because I feel. I am emotionally worse off when I come from there, it is too much.”]

The changes in the sufferers' personality after the diagnosis are especially hard for next of kin and adult children to handle (Kjällman-Alm et al., 2013:2). Due to the progressive nature of dementia, a person's cognitive skills continuously deteriorate and eventually they are unable to remember who anyone is, including a spouse, partner or other close relatives and friends (University of Western Sydney: College of Health and Science: School of Nursing and Midwifery, 2011:9), and this is truly devastating to all those involved. Furthermore, it is extremely common to see changes in the behaviour and emotions of people living with dementia, and it is very difficult to witness the person you once knew slowly changing into someone you do not recognise (University of Western Sydney: College of Health and Science: School of Nursing and Midwifery, 2011:11).

- **Sub theme 6.5: The AD diagnosis has an influence on all the systems of the adult child**

Families affected by AD experience a change in relationships, not only between themselves and the affected parent, but their other family members as well (Woolsey, 2013:200). A systemic view of the social network, particularly of family, recognizes that the experience of dementia impacts the whole family (Morhardt & Spira, 2013:37). Families affected by AD experience changes in relationships as well as dealing with emotional issues (Woolsey, 2013:200). Participants reported that their parents' AD diagnosis has not only had an impact on their relationships, but also on their wellbeing and daily lives. The impact of AD is not limited to the family system, the devastating effects of the disease places stress on the adult child's entire life, including and not limited to their careers, friendships and emotional wellbeing.

Most participants reported that the AD diagnosis had a negative impact on their relationships with family members, careers, and overall wellbeing.

Participant 3: *“Ander verhoudings met ag, met my oom hulle, my Pa se broer verstaan dit glad nie. Man, my Pa se broer is op die plaas saam met my, maar hy het nie vandat my Pa siek geraak het nog nie eenkeer eers gaan kyk of gaan gesels met sy broer of enige iets. So ons verhouding met my oom hulle het so bietjie ‘n knak gevat sal ek sê.”* [“Other relationships with ag, with my uncle them, my Father’s brother does not understand at all. Man, my Father’s brother is on the farm with me, but since my Father became sick, he hasn’t even visited him once or spoken to his brother or anything. So, our relationship with our uncle took a bit of a hit I would say.”]

Participant 5: *“My Ma kon glad nie met my dogtertjie wat op daai stadium twee was, sy’s baie lief vir haar gewees, daai verhoudingkie het baie skade gelei want, sy kon nie meer nie. Sy is besig, en sy hardloop rond en ouma kan nie lekker daarmee cope nie. Ek was swanger gewees toe my Ma gediagnoseer is en die tweede enetjie het my Ma nog as baba baie vasgehou en gesoen en so aan, maar toe hy nou ook begin ouer raak het kon ouma, ouma het ook mos nou baie agteruitgegaan, maar sy kon ook nie daarmee nie die besigheid hanteer nie. Tot op ‘n punt waar nou, ek kan glad nie meer my kinders na my Ma toe vat nie. So hulle ken my Ma op ‘n foto, maar hulle kan glad nie ouma toe gaan nie wat ouma kan nie, ouma kan nie dit hanteer nie, dis vir haar te veel.”* [“My mother could not be with my daughter who was two at that stage, she loved her very much, that relationship suffered a lot of damage, she could not anymore. She is busy, she runs around, and granny could not cope well with that. I was pregnant when my Mother was diagnosed and the second one my Mother still held and kissed him a lot as a baby, but when he also started to grow older granny also started to deteriorate, but she also could not handle that situation. So, they know my Mother on a photo, but they can’t go to granny at all because granny can’t handle it anymore, it is too much for her.”]

Participant 8: *“Aan die begin was dit baie erg gewees. Ek en my Ma het verskriklik baklei omdat ek dit ook nie verstaan het nie.”* [“At the beginning it was really bad. My Mother and I argued a lot also because I didn’t understand it.”]

Participant 10: *“In onse gemeenskap is dit amper ongehoord dat, onse ou mense gaan nie ouetehuse toe nie, dit voel amper jy gooi jou ouer weg. Maar wat die grootste deurbraak dink ek wat daarin was is die feit dat Mamma het 24 uur sorg nodig gehad en ons kan nie vir haar 24 ure sorg gegee het nie. Dit beteken of een van ons moet onse werke bedank en vir Mamma voltyds kom oppas of ek en my man en kinders moet hierna toe kom trek en wat ook ontwrigtend kan wees want my huwelik kan daar onder lei. Ja, so toe het ons toe nou familie vergadering gehad en dit was glad nie maklik nie. Obviously het ons die positiewe op die tafel neergesit en die negatiewe en die grootse negatief was, was die feit dat Anna het nie ‘n lewe van haar eie nie, sy het nie ‘n lewe van haar eie nie want sy gaan werk toe en sy gaan huis toe, sy kan nie eers kerk toe gaan nie, sy kan geen kerklike aktiwiteite deel neem aan dit nie want sy moet by Mamma bly. Dit was die grootste faktor wat, wat bygedra het om te besluit dat dit is die beste om vir Mamma in ‘n care centre te sit, en dan ook die mense wat by die care centre is is opgelei om, om na iemand om te sien met Mamma se kondisie.”* [“In our community it is unheard of, our old people do not go to old age homes, it almost feels like you’re throwing your parent away. But I think the biggest breakthrough was the fact the Mommy needed 24-hour care and we can’t give her 24-hour care. It means that one of us would have to resign from our jobs and come look after Mommy full time or me, my husband and my children need to move here and that can also be disrupting, and the marriage can be affected. Yes, so as a family we held a meeting and it wasn’t easy at all. Obviously we put the positives and the negatives on the table and the the biggest negative was, was the fact that Anna does not have a life of her own, she does not have a life of her own because she goes to work and she goes home, she can’t even go to church, she can’t take part in any church activities because she needs to stay with Mommy. That was the biggest factor that contributed to the decision that it is the best to place Mommy in a care centre, and then also the people who are at the care centre are trained to, to look after someone with Mommy’s condition.”]

An AD diagnosis severely impacts all areas of the adult child’s life and from the moment their parent receives the diagnosis they often face traumatic transitions: “being a concerned relative, becoming a carer, a visitor at a nursing home and a grieving survivor”. (Cronfalk, Ternstedt & Norberg, 2017:3520). When a family member is

diagnosed with AD communication, relationships and roles within the family are affected (Cronfalk et al., 2017:3520).

5.2.2.6. Role reversal

Dementia often has a direct impact on the roles that individuals hold as well as the sense of identity they have within the relationship, and when the responsibilities they held within a relationship are taken over people living with dementia experience a loss of independence (Miskovski, 2017:5). Children and spouses who have the responsibility of caring for their loved one living with dementia often feel like their roles have been reversed and that they are now parenting their parent or spouse, and others feel that they are merely there to act as the primary caregiver (Miskovski, 2017:5). These role changes, which can often occur suddenly and without warning, can directly impact on the individual's sense of identity within their relationships and within society (Miskovski, 2017:5).

5.2.2.6.1. Main theme 7: When parents grow older the adult child's role changes

Woolsey (2013:198) states that when a parent is diagnosed with AD the adult children often assume the caregiver role. Caring for a parent with AD is difficult, and it has been compared to caring for an infant (Woolsey, 2013:198). Adult children often assume the caregiving role out of obligation and love, and these close family ties and obligation are often the driving force between the role reversals between Alzheimer's patients and their adult children (Woolsey, 2013:198). A shift in one's inner world and identity and a reorganization of major life roles are almost inevitable accompanied by disequilibrium in one's central relationships inside and outside the family. From a systemic view of individuals and their social environments, there are consequences all through the family system when an individual struggle with major life change (Cowan & Cowan, 2016:430).

Participant 1 stated that before her diagnosis her mother used to be the one who prayed for all the children and who kept the family together. Although she knows that she can never fill the void left by her mother, she can support her siblings and cover them in prayer like their mother taught her to do. *"Ek sal nooit my Ma se plek kan*

volstaan nie, nooit maar nooit. Ek is die oudste meisiekind, maar dit wat Mamma vir my gelees het, die voorbeeld wat sy vir my gegee het, ek kan vir hulle bid, vir elkeen van hulle.” [“I will never be able to fill my mother’s shoes, never ever. I am the oldest daughter, but that which my mother taught me, the example that she was for me, I can pray for them, for each of them.”]

- **Sub theme 7.1: The adult child attempts to fill the void left by the parent**

One participant mentioned that after their parents were diagnosed and placed in the care of ADN, they attempted to fill the void that their parent left. As the eldest sibling, Participant 1 felt she needed to take on her mother’s role especially when it comes to special events like her siblings’ birthdays. She attempted to fill the void left by her mother by taking care of her family’s emotional needs. She also strived to reach out to her mother’s closest friends and take over the role she played in their lives.

“Die kinders kry swaar veral as hulle verjaar want dit was altyd die eerste oproep, die eerste oproep het altyd van my Ma en Pa afgekom, heel eerste. Marlene (Mari) sê byvoorbeeld somtyds het haar man haar nog nie eens geluk gewens nie dan het Mamma haar al gebel. Baie kere dan bel ek maar, daai wakker skrik, want ek weet nou presies wanneer hou hulle stiltetyd en ek weet wanneer is hulle nou al aan die gang, voorbereid om skool toe te gaan, dan bel ek maar daai tyd. Maar ek herinner hulle daaraan dis.* [“It is difficult for the children especially on their birthdays, because it was always the first telephone call, the first telephone always came from my Mother and Father, the very first. For example, Mari says sometimes when Mommy phoned her her husband had not even wished her a happy birthday yet. Very often I call, that moment I wake up, because I now know exactly when they have quiet time and I know when they are already on the go, ready to go to school then I call that time. But I always remind them that, that it isn’t Mommy.”]

- **Sub theme 7.2: The adult child becomes the parent to their parent with Alzheimer’s**

Adult children of older parents with dementia provide considerable physical care in the form of assistance with daily tasks, and they are often forced to provide financial

assistance to cover the high cost of medical, nursing, and respite care for their parent (Pan, Lee, Dye & Roley, 2017:109). As the disease progresses, people with dementia may no longer have the capacity to make important decisions about their health, wellbeing or finances. Although it is a sensitive and uncomfortable discussion to have, adult children and their older parent with dementia need to talk about the changes and obstacles that lie ahead and what role the adult child will play once the parent no longer has the capacity to make his or her own decisions. As the disease progresses and the older parent slowly deteriorates, the adult child will need to make all the decisions on behalf of their parent living with dementia, and this includes all decisions about the medical treatment the person living with dementia needs as well as any financial decisions that need to be made (University of Western Sydney: College of Health and Science: School of Nursing and Midwifery, 2011:6).

This was the case for Participant 5 who mentioned that since her mother's diagnosis a lot of responsibility has been placed on her shoulders and it has negatively impacted the relationship between herself and her mother.

“So dit was maar bloot, baie van die verantwoordelikheid het nou op my kom rus. Dit verander jou hele lewe bietjies vir bietjies want daar is klein goedjies wat van haar af weggeneem word wat ewe skielik op jou geplaas word. Verhoudingsgewys, tussen my en my Ma, dit het net daai omkeer sterker bevorder want ek is nou die ouer en sy is nou half die, die een wat moet luister. dit is die ander ding wat ons toe nou begin bekommered raak het toe ons nou begin agter kom het dinge gaan agteruit, is met die finansies omdat sy die enigste een wat oor is en nou, weet al haar bankrekeninge en al haar lewenspolisse en al daai goeters moet na gekyk word. Die testament, ons het haar power of attorney en haar testament binne 'n kwessie van ek dink ses of sewe maande het ons opgestel gekry en gefinaliseer gekry. Stap nommer twee jy weet, okay, bankkaarte. Ek het een bankkaart afgevat en net vir haar ene gegee en haar gerantsoeneer met haar geldjies want, ek was later bang sy trek al haar geld uit haar bankrekening uit omdat sy net eenvoudig nie kan onthou nie.” [It was simply, a lot of the responsibilities came to rest on my shoulders. It changes your life little by little, because there are small things that get taken away from her and are suddenly placed on you. Relationship wise, between me and my Mother, it just promoted that role reversal even more because I am now

the parent and she is kind of the one that must listen. That's the other thing that started to worry us when we started to realise that things were deteriorating, was with the finances, because she is the only one who is left and now, you know all her bank accounts and life cover policies and those things must be looked at. The will and testament, we got her power of attorney and will and testament we got set up within I think six or seven months. Step number two you know, okay, bank cards. I took away one bank card and I limited her with her money because later I was scared that she was going to withdraw all her money out of her bank account simply because she can't remember.”]

Participant 7 mentioned that she sometimes felt like she needed to step in and take over the role as parent because she felt sorry for her mother and what she had to deal with after her father's diagnosis.

“Ja, partykeer. Ek het al so baie probeer gaan kuier maar dit het so gevoel want ek het my Ma ook so jammer gekry. Dit het gevoel ek moet help, ek moet inspring.”

[“Yes, sometimes. I have tried to go visit so many times, but it felt like that because I also felt so sorry for my Mother. It felt like I needed to help, I needed to jump in.”]

Participant 8 mentioned that she has a younger sister who she has been forced to take responsibility of since her mother's diagnosis. Although her sister is 48 years old, she has never had a job and is now forced to work and earn an income. As a result, Participant 8 feels that she has to provide for her sister, because if her mother was still able to she would have ensured that her sister was taken care of.

“Ek het, ek het 'n jonger sussie. Ons is aangeneme kinders, ek en sy. Toe trou sy 'n man, die skeisaak is nou, sy moet nou net teken dan is dit verby en sy is nou my verantwoordelikheid. Sy't in al hierdie jare nog nooit gewerk nie, sy is nou 48 en sy moet nou vir die eerste keer werk. So, dis vir my, en ek moet nou vir haar sorg.” [“I have, I have a younger sister. We are adopted children, me and her. She then married a man, the divorce case is now, she must just sign then it is over and she is now my responsibility. In all these years she has never worked, she is now 48 and now she must work for the first time. So, for me it is, and I must now look after her.”]

Although some participants reported that they took over the role of parent after their parent was diagnosed with AD, Participant 6 stated that he never felt that he had to take his father's place or fulfil his role. *"Nee, glad nie. Nee, nee."* ["No, not at all. No, no."]

Participant 9 similarly asserted that she does not feel that she had to take over her mother's role or that she had to become a parent to her parent. She was never in the position where she had to physically take care of her mother, so she was never had to take on the role as care giver.

"Weet jy, ek was nooit in die posisie gewees dat ek haar versorg het nie want sy het by my Pa gebly obviously wat Ruth (Jane) baie versorging gedoen het, en toe van daar af is sy ouetehuis toe, van daar af is sy na Berrie toe. So ek was nooit in 'n volledige versorgings rol nie, maar emosioneel absoluut, ja."* ["You know, I was never in the position that I had to look after her because she lived with my Father and obviously Jane mostly looked after her, and from there she went to the old age home, from there she went to Berrie. So, I was never in a full care taker's role, but emotionally absolutely, yes."]

Some of the hardest things for adult children managing dementia involve balancing worry and the realization that roles have changed (Greenberg, 2017). To be an adult child of a person with dementia means to be compelled to take on the parental role for your mother or father with all that this entails like personal hygiene, economy, and safety. At the same time, you mourn the loss of that parent and long for them to return, and to feel close to them again. You are also faced with working double shifts to take care of your parents' household as well as your own, making sure that the healthy parent is coping with all the extra chores and helping with cleaning, washing, and care whenever possible. There is a sense of powerlessness, abandonment, and loneliness but also anger against the demented parent at how they changed and all the crazy things they do. There is also a presence of fear: fear of inheriting the disease. Additionally, there is longing for what has been (the previous relation) and missing the way you communicated with them before the disease (Kjällman-Alm et al., 2013:4).

- **Sub theme 7.3: Adult children experience numerous emotions related to the role reversal**

Participant 5 stated that her relationship with her mother completely changed as she was forced to take on the role as the caregiver and responsible one. The role reversal caused a lot of tension and led to many arguments between her and her mother. She further mentioned that because of the deteriorating effect of the disease the relationship between her and her mother is non-existent.

Participant 8: *So as my Ma gelewe het sou my Ma ek glo vir haar finansieel ondersteun het, maar nou wat ek my Ma se vier miljoen rand se Trust moet ek nou hanteer asof my Ma dood is en iemand iets laat kry terwyl my Ma nog lewe want dit is daar, dis meer as genoeg. Dis vir my emosioneel 'n geweldige besluit, maar ek glo nie my Ma sal vir my kwaad wees as ek vir my sussie per maand iets gee van haar geld nie want ek dink sy sou dit gedoen het. So dit, daar is vir my baie emosienele dinge by hierdie ding betrokke.* ["So if my Mother was still alive I believe my Mother would support her financially, but now that I am responsible for my Mother's four million Trust I must now handle it as if she is already dead and give someone something whilst my Mother is still alive because it is there, it is more than enough. Emotionally it is an enormous decision for me, I do not believe my Mother would be angry at me if give my sister some of her money monthly because I think that is what she would have done. So, there are many emotional things involved with this."]

Although it is not possible to say how long the PWD will live or to what extent their dementia will progress it is important to note that dementia is a progressive disease that severely impacts all facets of the PWD life, and changes in the way they communicate, remember, think and manage daily tasks should be expected (Alzheimer's Society of Ireland and the Irish Hospice Foundation, 2015:2). Changes brought about by dementia are not limited to the PWD, and families need to realise that although these changes happen gradually, they will need to adjust both practically and emotionally (Alzheimer's Society of Ireland and the Irish Hospice Foundation, 2015:2). The Alzheimer's Society of Ireland continues by stating that some of the changes caused by dementia often leads to the loss of independence for the PWD,

and family members are forced to take over they responsibility of tasks such as paying bills and legal paperwork, and this may be extremely overwhelming (Alzheimer's Society of Ireland and the Irish Hospice Foundation, 2015:2).

5.2.2.6.2. Main theme 8: There is a need for awareness raising and education about AD in Namibia

Mr. Berrie Holtzhausen first became aware of AD in 2009 when he opened his first old age home in Walvis Bay. Mr. Holtzhausen admits that when he first encountered the disease, he had no idea what it was or the devastating impact the disease has on the person living with it, their families and on society. He stated that there is a dire need for education and awareness raising in Namibia, and that he will continue to strive to teach Namibians about dementia and the impact thereof.

“Geweldig, geweldig. Dit sal nooit ophou nie en dis enorme groot. Dit is waaraan ek baie, baie aandag gee. Dit laaste jare en hierdie ook, ek kry nou ‘n Nederlandse groep waar ons ‘n ooreenkoms hopelik gaan begin oor samewerking sodat ons verskillende vlakke awareness kan doen, want die skole dink ek is bitter belangrik want ek dink as ons die kinders grootmaak met hierdie seikte as normaal, as deel van ons samelewing, niks om oor skaam te wees nie dan dink ek gaan ons oor paar geslagte gaan ons ‘n ander land sien.” [“Greatly, greatly. It will never stop and it is enormously big. That is what I give a lot, a lot of attention to. The last few years and this one as well, I am hosting a group from the Netherlands where we can hopefully start an agreement about working together so that we can raise awareness at different levels, because I think the schools are very important because I think if we raise the children with this illness as being normal, as being part of our community, nothing to be ashamed of then I think we will see a different country in the next generations.”]

Participant 3's wife replied there is a great need for education and awareness raising of dementia in Namibia especially about the different types of dementia, the impact the disease has on the family, what lies ahead and the fact that it is a disease a lifelong disease.

“Kennis van die verskillende tipes. Kennis van impak, kennis van die feit dat dit ‘n lewendige dood is. Kennis. Voorbereiding. Ja, dit sal baie goed wees as hier ‘n sentrum of informasie area of soos ‘n, ‘n mediese sentrum kon hê wat net vir jou bietjie as jy kan gaan, al die dokters is daar met hulle kennis of die informasie sentrum is daar met kennis of iets.” [“Knowledge about the different types. Knowledge about the impact, knowledge about the fact that it is a living death. Knowledge. Preparation. Yes, it will be great if there if there is a centre or information area like a medical centre that just if you can go, all the doctors are there with their knowledge or the information centre is there with knowledge or something.”]

Participant 6 similarly stated that he believes there is a great need for education and awareness raising in Namibia and that more needs to be done to create this awareness.

“Daar moet op ‘n manier meer awareness gestig word vir hierdie.” [“Some or other way there needs to be more awareness raised for this.”]

Participant 9 responded that if people do not understand what AD is, they will not know how to treat the person living with the disease and you would not feel the need to try and change the person. She further stated that people are not aware of the disease because they were never exposed to it, they were never educated on what dementia is and therefore it is not something that comes up in conversation.

“Nee, nee hulle verstaan nie. As jy regtig verstaan het wat gebeur met daai persoon dan gaan jy hom nie probeer verander nie, jy gaan nie vir hom probeer lesse leer nie. My Pa het nog die laaste keer wat hy haar besoek het het hy haar aandag probeer trek. Moenie. Gee vir haar liefde. Wat dit miskien bietjie anders maak is iemand wat nie exposure het aan Alzheimer’s nie en iemand soos ek wat wel exposure het aan Alzheimer’s, ek dink ons dink ‘n bietjie anders oor goed in die sin van, iemand wat nie enige exposure het aan dit nie gaan nooit hierdie conversation hê van, ‘Wat as ek dit het’ nie” [“No, no they do not understand. If you really understand what’s happening with that person then you won’t try and change the, you’re not going to try to give him lessons. The last time my Father went to visit her he still tried to get her attention. Do not. Give her love. I think what maybe makes it

a bit different is someone who does not have exposure to Alzheimer's and someone like me who does have exposure to Alzheimer's, I think we think a little different about things in terms of, someone who does not have any exposure to it will never have this conversation of, "What if I have it?"]

Participant 10 stated that she believes in the power of education and that it essential that communities are educated on the disease and what it entails.

- *“Ek het op ‘n stadium vir Anna gesê dat ek wou met dominie Berrie, ja met Berrie gesels dat hy byvoorbeeld na onse kerk toe kom en met die mense kom gesels oor dementia en Alzheimer's want die mense is oningelig. Ek glo in education, hoe meer mense ge-educate word uhm oor dit, oor die siekte, hoe meer sal hulle beter verstaan waardeer byvoorbeeld ons as kinders gaan. Ek dink hulle sal ook beter verstaan dat dit beter is om iemand in ‘n centre te het waar daar mense is wat opgelei is om met die mense te kan werk”.* [“At a stage I told Annie that I want to speak to pastor Berrie, yes speak to Berrie that he comes to our church and speaks to the people about dementia and Alzheimer's because people are uninformed. I believe in education, the more people are educated about it, about the illness, the more they will better understand what we for example go through as the children.”]
- **Sub-theme 8.1: No information was made available to participants and they needed to educate themselves on AD**

Foley and Swanwick (2014:5) state that once a diagnosis of dementia is received, PWD and their family members have trouble in accessing information, navigating the health and social care system, and they often find that there is a lack of suitable services and support systems. It is important that health care providers not only assess the person living with AD, but also the caregiver and they need inform them of the available resources in their communities, which will help them care for their loved ones and receive assistance to cope with the pressures of caregiving and the need for support (Sansoni et al., 2013:243). Participants mentioned that due to the lack of education and that they were never aware of the disease they had to find information on AD and educate themselves on the disease and what they are to expect.

Participant 6: *“Maar ek het nog nooit daai tyd stadium het ek nog nie my gesteur aan Alzheimer’s nie of bietjie navorsing daarvoor gedoen nie. Ek het begin meer navorsing doen.”* [“But at that stage I never concerned myself with Alzheimer’s or did a little research. I started doing more research.”]

Participant 7: *“Ek het so bietjie geweet daarvan, maar ek moes baie leer daarvan en ek moet nogal sê Berrie het ons verskriklik baie gehelp, baie en ek het uit my eie baie gaan lees daarvoor, artikeltjies en jy weet waarvan af kom dit, hoe gebeur dit. So dan verstaan mens ook beter en jy weet ons het maar vir my Ma ook goedjies gestuur dat sy kan lees oor hoe om my Pa te hanteer en wat om te maak, ja die bietjie wat ons geweet het was te min. Dit was hopeloos, jy het net geweet wat behels die siekte maar niks meer nie.”* [“I knew a little about it, but I had to learn a lot about it and I must say that Berrie helped us a great deal, a lot and I started to read about it on my own, articles you know about where it comes from, how does it happen. So then one also understands it better and we also sent my Mother a few things so that she could read about how to handle my Father and what to do, yes, the little we knew was not enough. It was hopeless, you just knew what the sickness was about but nothing more.”]

Participant 2 stated that there was a time when she was ashamed of her mother’s behaviour, and it wasn’t until she read up on AD and educated herself on the changes that occur in personality and behaviour as a result of the disease that she started to understand her mother’s behaviour more.

“Ja, toe kom ek op ‘n tyd wat ek dit begin aanvaar het en weet jy hoe het ek dit aanvaar? Omdat ek meer bewus geraak het waarvoor dit gaan. Ek het baie gelees daarvoor... en die, ek het as kind of as jong mens nooit geweet daar bestaan iets soos Alzheimer’s nie, want niemand praat daarvoor nie. Vir my is dit verskriklik nodig gewees. Ek het onsettend gelees daarvoor. Elke ding wat ek kon in die hande kry oor Alzheimer’s sodat ek ook my Ma kan verstaan, en dat ek ook die ander mense verstaan.” [“Yes, then I came to a stage where I started to accept it and do you know how I accepted it? Because I became more aware about it. I read a lot about it and it, as a child or adolescent I never knew something like Alzheimer’s existed, because no one speaks about it. For me it was incredibly necessary. I read about it

extensively. Everything I could lay my hands on about Alzheimer's in order for me to also understand my mother, and that I can understand the other people.”]

Participant 4 stated that they did not know what AD entailed or what lay ahead for them. Her brother took charge and started to read up about the disease, and once they started to educate themselves on the topic, they knew what lay ahead and what they could expect

“En dan het mens begin oplees an Alzheimer's natuurlik en dan weet jy okay fine, dis nou die stappe wat gaan kom. Kyk ons was baie onkundig met Alzheimer's, so ons het die diagnose gekry, my broer het dadelik begin oplees en hy het vir my verduidelik en ons het gekyk en so aan.” [“And then one started to read up on Alzheimer's and then naturally you know okay fine, these are the steps that are going to follow. Llook we were very ignorant about Alzheimer's, so we got the diagnosis, my brother immediately started reading up on it and he explained it to me, and we looked at it and so on.”]

Participant 10 mentioned that when she started to realise that her mother was acting differently, exhibiting strange behaviour and that she was very forgetful, she decided to look up her mother's symptoms online as she had never been exposed to similar situations.

“Maar op daai stadium toe sê ek vir my man, ‘Hier is iets groot fout met my Ma,’ en toe begin Google ek. Sit nou die signs en symptoms in en die tekens en man ek lees toe op, en elke keer word Alzheimer's, Alzheimer's. Op 'n stadium het ek gesien dementia en dan die verskillende tipes dementia en toe sê ek vir hom alles wat ek insit kom by Alzheimer's dementia uit so vir my is dit 'n teken dat of Mamma is in die begin stadium of in die middel van dit en iewers op 'n kol moet ons iets doen om vir Mamma te help.” [“But at that stage I told my husband, ‘Something is wrong with Mom’, and then I started to Google. Put in signs and symptoms and signs and man I read up, and every time Alzheimer's, Alzheimer's popped up. At a stage I saw dementia and the different types of dementia and then I told him that everything I typed in comes back to Alzheimer's dementia so for me it is a sign that Mommy is

in the beginning phase or in the middle of it somewhere and at some stage we need to do something to help Mommy.”]

Very often the person diagnosed with dementia does not understand what the diagnosis entails, they do not have access to quality and informative information, and they do not have the necessary support (Gerontological Society of America, 2018:58). As a result, they begin their adjustment to their diagnosis by being told that they cannot or should not do certain things (Gerontological Society of America, 2018:58), and they are not provided with information, life lines or ways forward. Additionally, family members often do not fully understand what AD is or what impact the disease will have on themselves and their older parent, and as such they find it very difficult to make sense of the changes they see in their parent’s behaviour, personality and health (Gerontological Society of America, 2018:58). As such, it is of utmost importance that family members be informed of the resources available in their communities, which will support both the family member and the person living with AD (Sasoni et al., 2013:244).

- **Sub-theme 8.2: There is a need for awareness raising in Africa where different cultures have different beliefs**

In most parts of Africa dementia is confused with or considered to be witchcraft, and thus there is a great need for awareness raising and education about dementia in Africa. Currently, the language used in literature, the media and in communities create a distorted depiction of dementia and of persons living with dementia, and further strengthens broader stigmas and misconceptions of what living with dementia is really like (Swaffer, 2014:711).

Participant 7: *“Ja, ek dink so. Ek dink veral ons, ons, ons swart mense weet nie. Hulle weet glad nie, hulle ken dit glad nie. Ag en ek dink daar is baie wit mense wat ook nie weet nie. Hulle dink as jy net jou sleutels vergeet op ‘n plek dan het jy half dementia.”* [“Yes, I think so. I think especially our, our black people do not know. They do not know at all; they do not know it at all. Ag and I think there are many white people that also do not know. They think if you just forget your keys somewhere then you kind of have dementia.”]

Participant 8: *“En ek dink onder die swart gemeenskap dink hulle nogsteeds jy’s mal of getoor of iets. Ek meen hulle verstaan dit nog minder as ons”* [“And I think within the black community they still think you’re crazy or bewitched or something. I mean they understand it even less than we do.”]

Participant 10: *“Glad nie, glad nie. Ek weet van ‘n paar mense in Kuisebmond, ons bly in Kuisebmond in die swart woonbuurt, ek weet van ‘n paar mense wat dit het, wat nommer een nie die geld om in so centre te gaan gesit word nie, en dan weet ek obviously onse mense, die swart mense, as hulle iemand sien wat so reageer, vir hulle is dit witchcraft en dan ook die mense verstaan nie Alzheimer’s dementia nie.”* [“Not at all, not at all. I know of a few people in Kuisebmond, we live in Kuisebmond in the black neighbourhood, I know of a few people who have it who, number one, does not have money to be placed in such a centre, and then I obviously know our people, the black people, if they see someone that reacts like that, for them it is witchcraft and then also the people do not understand Alzheimer’s dementia.”]

- **Sub-theme 8.3: Medical practitioners and care givers are not educated or trained**

Due to the lack of education and stigma attached to dementia, the care provided to PWD is of a lower standard and care services are distorted (Swaffer, 2014:709). General practitioners are well placed to educate and inform PWD and their family members about the disease, what it entails and what they can expect to encounter as the disease progresses (Foley & Swanwick, 2014:5); yet participants were of the opinion that in Namibia medical practitioners and care givers are not adequately trained to care for people living with dementia or to provide support to their families.

Participant 11: *“Die tweede ding wat ek wil sê is jou personeel sal moet opgelei word om te verstaan wat hierdie siekte is, want daar lê in ‘n groot geleentheid vir awareness wat my aanbetref as die mediese mense hierdie siekte verstaan.”* [“The second thing that I would like to say is that your personnel will need to be trained to understand what this sickness is, because there is a big opportunity for awareness

raising as far as I am concerned if the medical professionals understand this sickness.”]

Globally, health care systems are faced with many challenges regarding chronic disease management, including how medical practitioners and care staff need to assist patients in their choices and how to improve the bio-psycho-social aspects of their health and well-being (Zabalegui et al., 2014:176). The number of elderly people has increased tremendously (Kloppers et al., 2015:247). The fact that the elderly has a greater chance of developing chronic diseases, plus the normal biological changes that accompanies old age, necessitates competent caregivers to care for them (Kloppers et al., 2015:247). Competency refers to “having suitable and sufficient knowledge, qualifications and experience in the field that caregivers work” (Kloppers et al., 2015:247). This means that competent care givers can understand and meet the special care needs of the elderly that they take care of. Kloppers et al. (2015:247) assert that since old age is accompanied by physiological, social and psychological changes, competent caregivers are a necessity to meet the ever-changing needs of this vulnerable population.

5.3. CONCLUSION

This study focused on answering the research question “What are the experiences of adult children, who made the decision to place their parents diagnosed with AD in the ADN Care Farm Namibia?” The findings were drawn from the interviews conducted with adult children, who have or had parents diagnosed with AD, as well as the founder of ADN. This was done to explore the experiences of adult children who were forced to place their parent living with AD in a care facility and how this disease impacted their relationships and their overall wellbeing.

Dementia is a universal disease and its impact is felt throughout the family system. For the adult child, it is devastating to witness the effect that dementia has on their older parent’s health and overall wellbeing, and there are many emotions that they face throughout the duration of the disease. Upon receiving their parent’s dementia diagnosis, all participants experienced some type of emotion such as shock, fear, disbelief, sadness, hopelessness, uncertainty and grief. These emotions often

continued to linger throughout the progression of the disease, and participants experienced these emotions to different degrees.

AD is one of the most prominent reasons for placement in a care facility, and participants in this study believed that it was in the best interest of their parent to place them in the ADN Care Farm where they receive around the clock care. As the disease slowly progressed and the older parent's condition continued to deteriorate, the institutionalisation of their parent was driven by the concern for their physical and financial wellbeing. Caring for a parent with AD is not a simple task, and the caregiver burden carried by the adult children was another central reason for deciding to place their parent in a place of care. Constantly worrying about an older parent's wellbeing, wondering if they are safe and out of harm's way, scheduling all activities and responsibilities around the older parent's health need, and being on call 24/7 added to the heavy burden that adult children had to carry.

This study further highlighted the fact that in Namibia there are not nearly enough support services or care facilities for PWD. Finding a care facility that provides around the clock care turned out to be more difficult than anticipated. Adult children reported on their bad experiences at normal old age homes, which left their older parent neglected and worse off than before. Participants initially had to navigate the unfamiliar waters of dementia care alone as they received no support from medical practitioners and physicians after receiving their parent's dementia diagnosis. This study shed light on the fact that there is a huge gap in dementia health care in Namibia. There are little to no dementia friendly environments for PWD, the facilities that are available are not prepared to care for the specific needs of PWD, and only a few individuals and families can afford to pay the hefty monthly costs of the facilities that are able to meet the specific care needs of PWD. One of the only care facilities that is able to provide PWD with 24/7 specialised care in Namibia is the ADN Care Farm situated in Swakopmund. Participants all mentioned that whilst in the care of ADN they never worry about their parents' safety, they know that their parents' physical needs are carefully met, and that they are receiving the best care. Caring for a parent with dementia is a difficult task and one's own needs are usually placed on the back-burner. However, in this study the adult children stated that since they made the decision to place their parents in the care of ADN they have been able to meet their own needs, take care of other important

responsibilities, and enjoy time away from home without feeling guilty or worrying that their parents are in danger or uncared for.

The decision to institutionalise one's parent is a difficult one to make, but participants mentioned that the support they received from family, friends and community members made the transition smoother and ultimately aided in them making a decision in the best interest of their parent. However, although most of the participants received support from those around them some mentioned that they were criticised and insulted by other family members for their decision. In some cultures it is still believed that if you place your older parent in an old age home or care facility you are "throwing them away" or abandoning them, and some participants were confronted with this view when they placed their parent in the care of ADN. The stigma attached to dementia and the fact that people do not understand the disease or understand the true impact of the disease means that PWD as well as their families are isolated and pushed aside by family members, friends and community members.

This study further indicated that all relationships are tested and tried by an AD diagnosis. Relationships between the adult children and their siblings were either positively or negatively impacted by the AD diagnosis. Although participants mentioned that their relationships with their siblings were strengthened and their bond became much stronger, participants also reported that their relationships with their parents were negatively affected. The changes in the parent-child relationship was further accompanied by an immense sense of loss experienced by the adult child. Participants reported that they often experience a great deal of grief over the loss of their relationships with their parents and the fact that their parents are no longer part of their everyday lives and important life events. The change in their parents' behaviour and personalities is another aspect that adult children had to face, and participants reported that it was something that they found difficult to deal with. In this study it was made evident that as the disease progresses the adult child's role changes, and they are forced to take on more responsibilities and assume the tasks that were once their parents' responsibility. Some of the participants expressed that they often feel that they have been forced to become a parent to their parent.

It became evident that more needs to be done in Namibia to raise awareness about dementia and to educate people on the disease. Participants were of the opinion that in Namibia people do not know what dementia is, they have no knowledge about the different types of dementia, they do not know what the impact of the disease is on the PWD and their families or that it is a lifelong disease. Dementia carries a great deal of stigma and because people do not understand the disease and what its impact is, PWD are often ostracised and rejected by society. Participants further stated that when they received their parents' diagnosis no information was made available to them and they had to read up on the disease and educate themselves. Adult children felt that it is important to educate oneself, family members and the broader society to create a better understanding about dementia. Participants further voiced their frustration with the medical practitioners who treated their parents. They are of the opinion that the medical community do not know what dementia is, they provide no support to the adult child or the PWD, and they have no idea how to care for the PWD. Cultural differences and perceptions of mental health add to the stigmatisation of dementia, and as a result PWD are often neglected and abused. The importance of education was repeatedly stressed by participants.

This study provided an in-depth answer to the question "What are the experiences of adult children, who made the decision to place their parents diagnosed with AD in the ADN Care Farm Namibia?" Based on the findings, dementia is a universal disease that does not exist in isolation. It is a disease that is physically and emotionally draining, it robs a family of a parent and a grandparent, and due to its slow progression, the grief experienced never really goes away. The decision to place one's parent in a care facility is difficult and often accompanied by criticism and a lack of support. People with dementia and their families do not have access to support services in Namibia and they are forced to face the rocky waters by themselves. Namibia is still a long way from being dementia friendly and a lot needs to be done if people living with dementia are to be protected, treated with dignity and provided with specialised care.

CHAPTER 6

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1. INTRODUCTION

In Chapter 5 the researcher discussed the findings of the research study according to the qualitative approach. In this chapter the researcher will present the general summary of the research project, making conclusions and recommendations on the experiences of adult children who had to place their older parent living with dementia in a care facility in Namibia. Based on the themes and subthemes of this study, conclusions will be drawn and based on these conclusions, recommendations will then be made.

In the next section, the researcher will discuss whether, and to what extent, the research goal and objectives were obtained in this study.

6.2. RESEARCH GOAL AND OBJECTIVES

The goal of this research study was to explore and describe the experiences of adult children, who made the decision to place their parents diagnosed with Alzheimer's disease in a dementia care clinic in Namibia. The researcher formulated objectives to achieve the goal of the study and the achievement of the goal is evident through attaining the objectives. A discussion of the objectives follows:

6.2.1. Contextualising AD and the effect thereof on the individual and the family systems involved in the diagnosed individual's life

AD is a complex disease affecting all systems involved with the diagnosed individual. In Chapter 2 the researcher conducted an in-depth literature review contextualising AD and the impact thereof on the older parent, the adult child and the broader family system. The researcher approached this study from the Family Systems theoretical framework. This theory enabled the researcher to view the family and the dementia experience from a systemic perspective. The literature and empirical research

reiterated the importance of recognising the family as a whole that is greater than the sum of the parts, and this assisted the researcher to extensively report on the fact that AD threatens the functioning and the stability of the entire family system, with all its subsystems. In Chapter 2 the researcher also focused extensively on the phases of early, middle and late adulthood and how the relationship between a parent and child changes throughout the lifecycle.

6.2.2. Explore and discuss the effect that an AD diagnosis of a parent has on the adult child

Further to the above, also in Chapter 2, the researcher looked comprehensively at early and middle adulthood as phases which the adult child transitions through. People in the phase of the adult child are tasked with caring for their own children and spouses, establishing their careers and chasing their dreams. However, when their older parent is diagnosed with dementia, the adult children find themselves in the position of having to care for their parent or having to place them in a care facility. A dementia diagnosis can unsettle the dynamics of the entire family system, and in Chapter 5, based upon the empirical data, the researcher extensively reported on the effect that a dementia diagnosis of a parent had on the lives of the participants in this study.

6.2.3. Within the context of the Family Systems Theory, identify and discuss the impact that AD has on the relationship between the adult child and the ill parent

This objective was achieved by conducting an in-depth literature review on the parent-child relationship, how it changes throughout the life cycle, and how a dementia diagnosis ultimately changes the entire dynamic of the parent-child relationship. Although the parent-child relationship continues to change as both grow older, the relationship between a parent and a child remains one of the fundamental relationships in the life of both parent and child. Chapter 2 further expanded on how the role of the adult child often changes when the older parent is diagnosed with dementia, and what affect this role reversal and change in relationship has on the adult child. The empirical findings discussed in Chapter 5, further aided the researcher to report on the immense

impact that AD has on the relationship between the adult children and their parent living with dementia.

6.2.4. Explore and describe the impact the decision to institutionalise parents with AD has on adult children

Due to population ageing, AD is rapidly becoming a global epidemic. As the population continues to age and the number of older persons living with dementia increases, the need for care facilities and institutions will rise. Many older persons prefer to live at home and with their families, but as the disease progresses and the PWD continues to deteriorate they will eventually require continuous care which they often cannot get at home. In Chapter 1 the researcher discussed the reasons for institutionalisation, and how this decision affects the parent and the adult child. In Chapter 2 the researcher conducted an extensive literature review on the factors that forced the adult children to make the difficult decision of placing their parent in the care of the ADN Care Farm, and what the impact of this decision was on the adult child and the entire family system. In this study, the study population was limited to adult children whose parents are, or were, residents of the ADN Care Farm. However, although the study population was small, participants provided the researcher with rich data on the impact that the decision to institutionalise their parent had on them and their relationship with their older parent. This was extensively discussed in Chapter 5.

6.2.5. Identify and describe challenges faced by adult children in finding an institution, in Namibia, which will meet the specific and special needs of their older parents diagnosed with AD

In Chapter 3 the researcher comprehensively deliberated on the current shortcomings in the Namibian health care system with specific reference made to the lack of knowledge and skill pertaining to dementia care. The researcher further looked at the lack of mental health care services and facilities in Namibia, and how mental health is a right which should be protected and promoted. In Namibia quality health care is expensive and accessible only by those who can afford it. Adult children and families often do not have the means to provide their older parent with the care they need, and they simply cannot afford to place them in a care facility. Older persons with dementia

require specialised care which is expensive and scarce in Namibia. In Chapter 5 the researcher reported on the true experiences of adult children about identifying and finding a care facility that provides quality, specialised dementia care. These findings contributed to the recommendations for the need of quality and affordable dementia care, later in this chapter.

6.2.6. Explore and discuss the need for awareness raising and education about dementia and AD to address the stigma attached to the diseases

Globally, dementia is reported as being underdiagnosed, misunderstood and stigmatised due to a lack of knowledge. The need for awareness raising and education about dementia was continuously stressed by participants in Chapter 5. Protecting and promoting the personhood of someone with dementia is essential, but this will only be achieved if more attention is paid to raising awareness about dementia and the impact thereof. In Chapter 3 the researcher discussed how the traditional medical model and existing organization of health care failed to ensure that medical practitioners are able to care for and meet the specific needs of PWD and their families.

6.2.7. Draw conclusions and make recommendations, emanating from the research findings to service providers responsible for care management of older persons about resources available to family members of diagnosed older dementia and AD patients in Namibia

In this research study, the data collected regarding the state of dementia care services in Namibia, the impact that dementia has on the individual and the family, the need for quality dementia care services, and the importance of education will be used to make recommendations to service providers who are charged to care for the elderly and their families. Based on the research findings, which were systematically reported on in Chapter 5, the researcher will be able to make recommendations to the relevant Ministries and other organisations responsible for the care of older persons in Namibia.

Based on the discussion above, it is apparent that the goal and the objectives were met.

6.3. RESEARCH QUESTION

The research question formulated for this study was “What are the experiences of adult children, who made the decision to place their parents diagnosed with AD in the ADN Care Farm Namibia?” The study population was limited to adult children whose parents are, or were, residents at the ADN Care Farm, and as a result the Namibian context was not adequately explored. However, the opinions and experiences of the adult children mirrored those reported in existing literature, and the researcher was able to extensively report on the impact that AD has on the adult children and their relationship with their older parent. The research question of this study was answered.

The researcher will now report on the key findings of this research study.

6.4. KEY FINDINGS

6.4.1. Key findings: Family Systems theory

In this study the researcher made use of the Family Systems Theory to explore and discuss the dynamic interplay of family systems in view of an AD diagnosis.

- This theory enabled the researcher to view the adult child, the older parent and an AD diagnosis in the context of mutual interaction and mutual influence.
- An AD diagnosis in a parent does not only have a devastating impact on the older parent, but the overwhelming impact is felt throughout the family system.
- Participants functioned in their own subsystems and had relationships outside the larger family system, which were all effected by their parents’ AD diagnosis.

6.4.2. Key findings: Research methodology

- The research approach most applicable to this study was the qualitative approach, and this enabled the researcher to immerse herself in the living world of each participant, in the case of this research study the adult child of a parent diagnosed with AD.

- The applied research perspective was applicable as the researcher identified a specific gap in knowledge pertaining to AD and aimed to offer recommendations on how to close this gap.
- By making use of the phenomenological research design and due to the personal and intimate nature of one on one interviews, participants felt more inclined to share their personal experiences. The researcher would not have collected the same in-depth information if she had made use of a questionnaire.

The key findings pertaining to the emotions experienced by the adult children whose parents were diagnosed with AD will be discussed in the next section.

6.4.3. Key findings: emotions experienced by the adult children of parents diagnosed with AD

- Receiving a dementia diagnosis of a parent is not easy, and such a diagnosis can unsettle the entire family system. The initial emotions experienced by participants were mostly negative.
- Initial shared emotions experienced by participants when they received their parents' diagnosis were shock, fear, ignorance, uncertainty, disbelief, sadness, and hopelessness.
- Continuous emotions experienced by most participants included shock, disbelief, and eventual acceptance.
- Being unable to repay one's parents for all they have done throughout the years left participants with a sense of helplessness, anger and guilt.
- Although most of the emotions experienced by participants were negative, some participants reported positive emotions in hindsight, such as relief and acceptance.
- Guilt was a common emotion experienced by many of the participants. Participants felt guilty for placing their parents in a care facility and they felt like they were abandoning their loved one.

The researcher discussed the various emotions experienced by participants throughout the dementia journey. The next section will focus on the decision made by all participants to have their parents admitted at the ADN Care Farm.

6.4.4. Key findings: placement of an older parent in ADN Care Farm

- Placing one's parent in a care facility is a difficult decision to make.
- All the participants stated that, although difficult, they do not regret placing their parents in the care of ADN. Participants all felt at ease knowing that their parents are in good hands and well cared for.
- The slow progression of AD is one of the primary factors that led to adult children placing their older parents in the care of ADN.
- Contributing to the decision to place their parents in a care facility was the concern for their parents' physical and financial wellbeing, and the realisation that their parents would pose a great risk to their own, as well as others' wellbeing if they continued to function independently.
- Caregiver burnout was experienced by many of the participants and was a contributing factor to their parents' institutionalisation. The caregiver burnout was also experienced by some of the participants' siblings or healthy parents, and this was a concern to participants.

The researcher discussed the reasons behind adult children placing their older parent with dementia in a care facility. The next section will focus on the lack of specialised care facilities in Namibia for PWD.

6.4.5. Key findings: lack of facilities specialising in Alzheimer's care in Namibia

- In Namibia, there are not adequate care facilities that offer specialized care for PWD, and participants found it difficult to identify a care facility where their parent with dementia would receive quality care.
- Normal old age homes are not able to adequately meet the extensive care needs of PWD, and most participants expressed their unhappiness with the treatment and care their parents received at these old age homes.
- Care facilities that are available are expensive and can only be afforded by those individuals who have enough money to cover the monthly costs.

In the next section, the researcher will focus on the specialised care required by people living with AD.

6.4.6. Key findings: specialised care required by people living with AD

- As the disease progresses, PWD require a great deal of personal and specialised care, which they often cannot receive in their home environment.
- The ever-growing care needs of PWD contributes to the caregiver burden experienced by participants
- At the ADN Care Farm, the physical needs of residents are adequately catered for and adult children are assured that their parents' wellbeing is promoted and protected.

The next section will focus on the support, or lack thereof, received by adult children when they made the decision to place their parent in the care of ADN.

6.4.7. Key findings: support received when older parent was placed in ADN care farm

- The decision to place their parents with dementia in a care facility was one that participants did not make lightly, but the support received from family, friends and the broader community made the transition a little easier.
- In many societies and cultures adult children are expected to care for their older parent at home, and the decision to institutionalise a parent living with dementia was therefore often met with a lack of support and criticism.
- Dementia still carries a great deal of stigma in many societies, and the family members of PWD often face the same discrimination as their loved one and are equally likely to be socially excluded.

AD has an impact on all relationships of PWD, and in the next section the researcher will discuss the impact that their parents' AD diagnosis had on the adult children's relationships with those around them.

6.4.8. Key findings: impact of AD on relationships

- A dementia diagnosis directly impacts relationships throughout the family system; and whether positive or negative, all participants experienced some change in their relationships.
- Their parents' AD diagnosis had both negative and positive impacts on the relationships between siblings. However, most participants expressed that since their parents' diagnosis their relationship with their siblings were strengthened and they were much closer than before.
- In this study AD showed to influence personal communication, affecting the parent-adult child relationship. Adult children reported feeling like the relationships they had with their parents before the AD diagnosis drastically changed and they no longer experience a normal parent-child relationship.
- Although most participants reported that AD had a negative impact on their relationship with their parents, some participants mentioned that since their parents' diagnosis they feel that their relationship has improved and grown stronger.
- Changes in relationships are further accompanied by an immense sense of loss. Adult children grieve the changes brought about by AD such as the change in the quality of their relationships with their parents. Adult children grieve the fact that their parents are no longer the people they were before AD, the fact that they can no longer ask advice from their parents or have meaningful conversations with them are losses that adult children find difficult to deal with.
- AD changes the personality of the person living with the disease, and adult children mentioned that they miss the person their parent once was. Watching their parents deteriorate in front of their eyes is something that participants struggled to deal with.

6.4.9. Key findings: role reversal experienced by the adult child when a parent grows older

- Participants in this study all fall within the developmental phase of middle adulthood. Participants have their own families and responsibilities, but as the disease progressed most of the adult children experienced a sense of role reversal. Adult

children became the parent to their parent, and they had to take on additional responsibilities.

- Some of the participants mentioned that as their parents' condition continued to deteriorate, they were forced to fill the void left by their parents.
- Being in a position where one needs to take on the responsibilities of an older parent often results in tension and frustration in the parent-child relationship.

6.4.10. Key findings: need for awareness raising and education about AD in Namibia

- There is an immense knowledge gap about dementia in Namibia. Most people do not know what dementia is. They are unaware that there are many types of dementia, and they do not realise that there is an ever-growing number of PWD.
- In Namibia, as in most African countries, people do not understand dementia and as a result, PWD are often stigmatised and isolated. There is a great need for awareness raising and education about dementia in Namibia.
- After receiving the diagnosis, PWD and their family members experience difficulty getting hold of information, finding their way in the health and social care system, and often have no access to support services. Participants stated that after receiving their parents' diagnosis, they were forced to educate themselves as they received no assistance from any of the medical professionals who treated their parents.
- In Africa, dementia is still considered and referred to as witchcraft. These beliefs and misconceptions are due to a lack of knowledge and no education about dementia.
- PWD often receive a lower standard of care due to the lack of education and stigma attached to dementia. Medical professionals do not understand the disease; they have no knowledge of the impact dementia has on the entire family system, and as a result they are unable to provide PWD and their family members with the necessary support.

6.5. CONCLUSIONS

In view of the completed research study, the researcher will discuss conclusions.

6.5.1. Research methodology

In conclusion, the researcher wants to emphasise that for the purpose of this study the qualitative research approach was most applicable as it focused on the living experiences of participants. It allowed the researcher to immerse herself in the experiential world of each participant and strengthen the applied research perspective, whereby the researcher identified a specific concern to be investigated. The phenomenological design ensured that the researcher viewed the impact that AD has on the parent-child relationship from the adult child's perspective and experiences, and the one on one interviews enabled the adult children to share these personal and intimate perspectives and experiences with the researcher. A quantitative research approach would not have been suitable for this study.

6.5.2. Emotions experienced by the adult children of parents diagnosed with AD

Receiving a dementia diagnosis is not easy, and many emotions are experienced once PWD and their families are informed of their condition. These emotions are not only experienced when the diagnosis is received, but instead they accompany the adult child throughout the dementia journey. Most emotions associated with the dementia journey are negative, but some participants reported experiencing positive emotions somewhere along the line. Although the adult children shared a common experience, i.e. a parent being diagnosed and living with AD, each child experienced and reacted to this phenomenon in a personal and unique way. It can be concluded that families where a parent or family member is diagnosed with dementia and/or AD need specialised care and intervention.

6.5.3. Placement of an older parent in ADN care farm, the specialised care required by people living with dementia, and the lack of specialised care facilities in Namibia

After the diagnosis of AD adult children had to make the decision to place their older parent living with AD in the ADN Care Farm where they would receive continuous care, and none of the participants regret their decision. Although most older persons and their family members would prefer that their loved one remains in the loving home

environment, they realised that living with dementia will eventually require 24/7 care. PWD eventually experience great difficulty in, or are simply incapable of, meeting their basic needs such as taking a bath, brushing their teeth, getting dressed or preparing a meal. As their condition deteriorates, the need for specialised care increases and family members are forced to find a care facility that is equipped to meet their parents' extensive care needs. With the number of PWD on the increase the Namibian health care system is not equipped to cater for their needs since there are simply not enough specialised care facilities for PWD, and adult children mentioned experiencing great difficulty in finding a care facility that they know will take great care of their older parents.

6.5.4. Support received when older parent was placed in ADN care farm

The adult children who made the decision to place their older parent living with AD in a care facility believed, when they received support from those around them made it a little easier to make this difficult decision. However, in many cultures, children are still expected to care for their older parent, and when the adult child made the decision to place their parent in a care facility they were often met with criticism and a lack of support from those around them. Adult children were confronted by family and community members when their parent was moved to the ADN Care Farm, and along with their own morals and beliefs, these adult children felt guilty and believed that they had "thrown their parents away". Dementia and AD still carry a great deal of stigma, and as a result PWD and their families find themselves alone and isolated. In Namibia there are no support services available for PWD or their family members.

6.5.5. Impact of AD on relationships

Dementia is a foreign concept to most people in African countries, and this is mostly because people do not possess the knowledge and understanding of this neurological condition. The impact of AD is not limited to the PWD, but instead this neurological disease has a direct impact on all relationships within the family system and its unique subsystems. Adult children mentioned that since their parents' diagnosis the parent-child relationship completely changed, their parents' personalities changed, changes in behaviour were observed, and the quality of the parent-child relationship was

negatively affected. Some participants mentioned that their relationships with their parents are now more fun and filled with more empathy, but most participants spoke of a great loss experienced as the disease progressed. Relationships with siblings were also affected, some positively and some negatively. Most participants mentioned that their parent's diagnosis brought the siblings closer and their relationships with one another have been strengthened. It is concluded that AD can derail all relationships within in the family system, and most participants did experience some derailment within their relationships, especially the relationship between the adult child and the older parent with dementia. AD is a family disease, and the devastation it leaves behind ripples throughout the family system.

6.5.6. Role reversal experienced by the adult child when a parent grows older

As an adult in the developmental phase of middle adulthood, each participant had their own families and responsibilities which they had to accommodate. However, most participants reported experiencing some degree of role reversal between themselves and their older parent living with AD. As the disease continued to progress and PWD begin to lose more and more cognitive functioning, adult children are often forced to take on the role of the parent and subsequently, the adult child becomes a parent to their parent. Adult children often find themselves trying to fill the void left by their parent, and along with the role reversal that often takes place the conclusion is made that the entire family dynamic is changed.

6.5.7. Need for awareness raising and education about AD in Namibia

A lack of awareness raising, and education has resulted in dementia, and other neurological disorders, often considered a form of witchcraft. The researcher concludes that these beliefs further stigmatise dementia, and as a result PWD are often isolated, mistreated and abused. When confronted with an AD diagnosis, most adult children found themselves in place of total ignorance and confusion, and they were forced to educate themselves on the disease and what lay ahead. Based on experiences reported by participants, most medical professionals possess little or no knowledge about the disease and this results in PWD receiving the wrong treatment, wrong advice, no support and leaves family members to their own defences.

6.6. RECOMMENDATIONS

With the number of PWD continuously increasing, more needs to be done to protect the rights of those living with dementia, to ensure that their care needs are met, to break away from the stigma attached to dementia, and to provide support for PWD. The following recommendations are based on the empirical findings.

6.6.1. Recommendations for future research

The following has been identified as recommendations for future research:

- This is the first study that will be published in Namibia about the experiences of adult children who had to place their parent living with AD in a care facility, and therefore the research gap remains extensive. Although the researcher extensively explored and reported on the experiences of adult children, these findings do not accurately represent the entire Namibian context.
- The sample size of this study was limited to eleven participants, and the researcher strongly recommends that for future research a larger sample size should be obtained.
- Research should be conducted with participants from different communities and cultural backgrounds in Namibia. This should be done to identify and explore the many views, misconceptions, perceptions and knowledge that exist of neurological conditions such as dementia.
- The extent to which old age homes and residential care facilities are equipped to meet the care needs of PWD in Namibia should be explored.
- More research needs to be done to identify the specific care needs of PWD, and the types of support services required by family members of PWD should be identified.

6.6.2. Recommendations for practice

The following recommendations are made for practice:

- Information packages on dementia, the different types of dementia, what to expect, and the different support services and resources available to PWD and their family

members should be available in all medical practices and hospitals. These information packages should be printed in all Namibia's different dialects.

- The researcher can play an instrumental role to discuss the findings of her study with Ministries to take the lead in the printing and distribution of the above materials.
- Support services need to be availed to PWD and their family members. Group work and support groups should be considered as effective support mechanisms for PWD and their family members.
- Dementia needs a systemic view and approach since the disease affects all systems linked to the diagnosed individual.
- Awareness raising and public education on dementia should receive national attention. Advocating for the rights of PWD will only be effective if people are aware of the disease, have knowledge about what it entails and understand that dementia is a neurological condition, not a curse or an indication that the PWD is a witch.
- Social workers, psychologists, occupational therapists, nurses, care workers, medical practitioners and all other individuals tasked to care for the elderly need to be sensitised on dementia, be aware of the different symptoms of dementia, learn to understand the disease and how to care for PWD, and they need to be able to support family members of PWD.
- Person-centred care must be a guiding principle and the unique worth of the person needs to be acknowledged in every individual, regardless of cognitive impairment.

6.6.3. Recommendations for the Government of the Republic of Namibia

The state is tasked with protecting the rights and dignity of all citizens, and to ensure that citizens living with dementia and their family members enjoy the same protection, the researcher recommends the following:

- The Frail Care Policy that has been in the pipeline needs to receive the attention it is due. Older persons in Namibia appear to be part of the forgotten people, the maltreated, neglected and abused. The state and ministries tasked to protect and promote the rights of this vulnerable population, are instrumental in ensuring that a policy be put in place.

- Old age homes which receive state funding need to be up to standard and must be able to meet the needs of all older persons, including those living with dementia and AD.
- Medical staff and caregivers who are employed in public hospitals and clinics need to be educated on dementia, sensitised to the symptoms of dementia, and how to meet the care needs of PWD. Medical staff need to be taught that the care needs of PWD need to be met in a manner where the person with dementia is treated as someone with value, and always treated with dignity and support.
- It is recommended that secondary school children already receive information about mental health; they need to be aware of the different neurological diseases, and they need to be taught that all people, regardless of their condition, are human beings who deserve to be treated with respect. An addition to the existing secondary school curriculum on life orientation is therefore proposed.

6.7. CONCLUDING REMARKS

A growing older population is imminent and specialised care is needed, especially in the case of a dementia and AD diagnosis. Family members of PWD experience immense changes and challenges and this research study emphasises the necessity of addressing the need.

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APPENDICES

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APPENDIX 1: RESEARCH AND ETHICS COMMITTEE PERMISSION



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

30 September 2016

Dear Prof Lombard

Project: Living with Alzheimer's disease in Namibia: The adult child, the older parent and the decision to institutionalize
Researcher: E Pretorius
Supervisor: Prof CE Prinsloo
Department: Social Work and Criminology
Reference number: 10361508 (20160921HS)

Thank you for the **well written** application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 29 September 2016. 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 Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Dr L Dlokiand; Dr R Faase; Ms KI Govindor; Dr E Jolissen; Dr C Panobianus; Dr C Pullerg II; Dr D Ruyburn; Prof GM Spies; Prof E Taljard; Ms B Tsebe; Dr E van der Kleef; Mr V Sthole

APPENDIX 2: LETTER OF INTENT



Faculty of Humanities

Department of Social Work & Criminology

15/07/2019

Our Ref: Prof CE Prinsloo

Tel: (012) 420-2601

E-mail: reineth.prinsloo@up.ac.za

Ref. Elmi Pretorius - student number 10351508

Tel. 0817781372

E-mail: pretoriuselmi@gmail.com

The Head

The ADN (Alzheimer's Dementia Namibia) Care Farm

P.O. Box 928

Walvis Bay

NAMIBIA

Dear Mr. Berrie Holtzhausen

REQUEST FOR PERMISSION TO PERFORM EMPIRICAL RESEARCH ELMI PRETORIUS - STUDENT NUMBER 10351508

I am a registered student for the following programme at the Department of Social Work, University of Pretoria: MSW (Research). I am required to write a dissertation, resulting from a research project, under the supervision of Prof CE (Reineth) Prinsloo. The research study has been approved by the Departmental Research Panel and will only proceed once the Faculty Research Proposal and Ethics Committee has approved the proposal and data collection instrument(s). The following information from the research proposal is shared with you, although a copy of the research proposal will be provided to you if needed.

The envisaged title of the study is: **Living with Alzheimer's disease in Namibia: The adult child, the older parent and the decision to institutionalise**

Department of Social Work & Criminology
Room 10-9, Level 10, Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2601
Fax +27 (0)12 420 2093
Email reineth.prinsloo@up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotheo

The goal of the study is to explore and describe the experiences of adult children, who made the decision to place their parents diagnosed with dementia/Alzheimer's in a dementia care institution in Namibia

The objectives of the study are:

- Contextualise Alzheimer's disease / dementia and the effect thereof on the individual and the family systems involved in the diagnosed individual's life.
- Explore and discuss the effect that an Alzheimer's disease / dementia diagnosis of a parent has on the adult child
- Within the context of the Family Systems theory, identify and discuss the impact that Alzheimer's disease/ dementia has on the relationship between the adult child and the ill parent.
- Explore and describe the impact the decision to institutionalize parents with Alzheimer's disease / dementia has on children.
- Identify and describe challenges faced by adult children in finding an institution, in Namibia, which will meet the specific and special needs of their older parents diagnosed with Alzheimer's disease / dementia.
- Draw conclusions and make recommendations, emanating from the research findings to service providers responsible for care management of older persons about resources available to family members of diagnosed older Alzheimer's disease / dementia patients.

The envisaged target group of the study is a group of adult children, both male and female, whose parents are or have been residents at the ADN Care Farm.

I intend to do the empirical part of the study through means of 10-15 open-ended, unstructured interviews with the identified adult children between the ages of 20 and 59 years whose parents were or are residents of your institution. This request will not result in any demands from you or your staff. No costs will be incurred by this request.

I undertake responsibility to provide you with a copy of the final report – if required.

It would be appreciated if you will consider this request and grant written permission (on an official letter head of your agency) to proceed with the project, at your earliest convenience.

Kind regards

Ms Elmi Pretorius

.....
STUDENT

APPENDIX 3: LETTER OF INFORMED CONSENT



Faculty of Humanities

Department of Social Work & Criminology

04/07/2016

INFORMED CONSENT

1. NAME OF RESEARCHER

Name: Elmi Pretorius

Tel: (+264) 81 778 1372

2. RESEARCH TITLE

Living with Alzheimer's disease in Namibia: The adult child, the older parent and the decision to institutionalise.

3. PURPOSE OF THE RESEARCH STUDY

The purpose of the research is to explore and discuss the experiences of adult children, who made the decision to place their parents diagnosed with Alzheimer's disease in a dementia care clinic in Namibia.

4. DESCRIPTION OF PROJECT

The aim of this research study is to explore and discuss the experiences of adult children, who made the decision to place their parents diagnosed with Alzheimer's disease in a dementia care clinic in Namibia. The researcher will conduct unstructured one-to-one interviews with the selected participants. The researcher will explore the experiences of adult children who had to make the difficult decision of placing their older parents diagnosed with this consuming disease in an institution; their experiences in finding a care facility for their now demented parents in Namibia; and their experiences of the impact of the decision to institutionalise their parents had on the parent-child relationship. The duration of the interview cannot be determined as the interview is unstructured and the duration will therefore be dependent on the willingness of the participants to share their experiences. Every interview will be recorded with a digital recorder for the researcher to be able to transcribe the content and analyse the research data. Participants are guaranteed of confidentiality and their responses will be anonymous in the final research report.

5. NUMBER OF PARTICIPANTS

Ten (10) to fifteen (15) participants will be selected to take part in the research project.

6. RISKS INVOLVED IN THE RESEARCH STUDY

This research study aims to explore and understand the deep, personal experiences of adult children in relating to their parents who have been diagnosed with dementia. The researcher is aware that engaging in a conversation relating to such personal and emotional experiences could trigger emotional and hurtful memories. For those who had an especially strong bond with the diagnosed parent, the questions could trigger lost memories and experiences, memories and moments, which the adult child may have stored away subconsciously.

Thus, the researcher will inform the selected participants that the line of questioning may trigger certain emotions and memories, and if they do not think they will be able to handle it, they are welcome to withdraw from the study at any time, whether before or during the process. The researcher will formulate the main question and probe participants in a manner that invites them to engage in a conversation, and not in a manner that makes them feel they might be judged when responding. Should the researcher pick up any form of emotional harm or distress, she will refer the participant to a counsellor identified in close vicinity to where the participant lives.

The participants will not be subjected to any intentional harm and the researcher will make every effort to conduct this research in a manner that will minimize possible harm, however, the researcher will conduct a debriefing session with every participant.

7. BENEFITS OF THE RESEARCH STUDY

There are no economic benefits for participating in this research project. However, the research findings will help shed light on health care facilities for the elderly in Namibia, as well as assist in identifying the impact of dementia on the relationship between the adult child and the parent.

8. VOLUNTARY PARTICIPATION

Although the researcher seeks my permission to be part of the research, it does not obligate me to do so. My participation is voluntary. I will be free to withdraw my participation at any point and will experience no negative consequences.

9. RECORDS OF PARTICIPATION IN THIS RESEARCH

The information provided will be protected and my responses will be kept confidential. Recordings and transcripts will be stored in a locked cabinet. The only individuals who will have access to this information will be those directly involved with this research project that have been trained in methods to protect confidentiality. The research information will be safely stored at the Department of Social Work and Criminology, University of Pretoria for a period of fifteen years for the purpose of research and for archiving. The results of this research may appear in publications, but participants will not be identified.

10. CONTACT PERSONS

If I want more information about this research, I may contact the researcher as indicated at the beginning of this document.

11. AGREEMENT TO PARTICIPATE IN THE RESEARCH STUDY

My signature indicates that I have read, or listened to, the information provided above and that I received answers to my questions. I have freely decided to participate in this research, and I know I have not given up any of my legal rights.

I hereby freely give my permission to participate in this research project.

This document was signed at _____ on the _____ day of _____ 2016.

NAME:

SIGNATURE:

SIGNATURE OF RESEARCHER:

Elmi Pretorius

APPENDIX 4: APPROVAL FROM MR BERRIE HOLTZHAUSEN

ADN
[Alzheimer Dementia Namibia]



E-mail: berrie.holtzhausen@gmail.com

Cell number: 081 283 3983

OUR MISSION

QUALITY OF LIFE FOR PEOPLE LIVING WITH DEMENTIA

19 April 2016

RE: REQUEST FOR PERMISSION TO PERFORM EMPIRICAL RESEARCH

ELMI PRETORIUS - STUDENT NUMBER 10351508

TO WHOM IT MAY CONCERN

I, the undersigned, hereby grant permission to Me Elmi Pretorius to perform empirical research in our Dementia care home in Swakopmund, as requested by her.

I am the CEO and founder of ADN [Alzheimer Dementia Namibia] and believe that a research study like Elmi's can help us to support the families of our 'family' much better.

Yours sincerely


Berrie Holtzhausen

APPENDIX 5: SEMI-STRUCTURED INTERVIEW SCHEDULE

Interview schedule:

Main question:

1. You made the decision to place your parent in the ADN Care Farm; what led you to ultimately make this decision?

Probing questions:

2. An Alzheimer's disease diagnosis is life altering and ultimately brings waves of sudden change in our daily lives. Your parent was diagnosed with this consuming disease, could you tell me more about how this disease has impacted your life, your relationships and your overall wellbeing?
3. What led to you ultimately consulting a physician on behalf of or with your parent?
4. How would you describe the emotions that followed when the physician informed you that your parent has Alzheimer's disease?
5. What was the first thing you had to consider after receiving the diagnosis?
6. Would you say that Alzheimer's disease impacted your relationship with your parent?

APPENDIX 6: QUESTIONS FOR DR BELINDA BRUWER: MENTAL HEALTH: STIGMA AND DISCRIMINATION

MENTAL HEALTH: STIGMA AND DISCRIMINATION

1. How long have you been practicing as a psychiatrist and how long have you been based in Namibia?
2. People with mental health disorders/conditions are often ostracised, stigmatized and discriminated against. Do you agree that there is a lot of stigma attached to mental health?
3. As a psychiatrist you deal with a wide spectrum of mental health disorders. Although not a normal part of aging many older persons will be diagnosed with dementia, and as the population continues to age more and more people will be exposed to the disease:
 - In your opinion, is the Namibian health care system equipped to deal with special and complex needs of people with dementia?
 - Are there enough facilities in Namibia that caters for the specific care needs of people with dementia?
 - Are there any support services that you are aware of for family members of people with dementia?